The Preparedness of Nursing Students in Caring for Cancer Patients:

The Cancer Caregiver Handbook

Karen E. Hickey

Department of Educational and Counselling Psychology

Special Activity Project Report submitted in partial fulfillment of the requirements for the degree

of Master of Education in Educational Psychology,

General Educational Psychology Concentration

Department of Educational and Counselling Psychology, Faculty of Education,

McGill University, Montreal, Quebec, Canada

Abstract

This project examines the extent to which nurses are prepared to care for cancer patients upon completion of their nursing studies. The literature review examined the need for augmenting the content of cancer care in nursing program curricula as well as identifying the specific areas that required attention. The need for supportive measures was also explored. Demographic variables that were included were age, level of education, and years of experience. Informal interviews were conducted with students and new graduates from the nursing program at John Abbott College in Montreal, Quebec generating the idea for a self-reporting questionnaire that was answered by 18 nurses employed in two oncology units in two hospitals in Montreal, Quebec. The results of this study suggest that nursing students and new graduates of college and university level nursing programs could be better prepared to care for cancer patients upon completion of their nursing program. The survey identified specific areas that required enhancement in nursing programs. The Cancer Caregiver Handbook was created as a result of the information acquired from the study to provide additional material to nursing students and nurses caring for cancer patients.

Summary

The oncology nursing textbook sitting on my desk is 1069 pages in length. As a college nursing teacher with experience as an oncology nurse clinician, I questioned how well the student nurses fared after graduation when assigned to care for cancer patients on their units. Did they feel comfortable and competent when relating to these patients with such specific needs? Was communication difficult for them? On the subject of cancer, the communication and care component in the curriculum of the nursing school I teach at is focused primarily on palliative care. I wondered how four hours of class time on cancer care in their final year could be sufficient enough to prepare them for the challenges faced when caring for cancer patients, in particular when communicating with them. Not convinced that it was adequate, I spoke to third-year students and conducted a survey to find out how new graduates and practicing nurses felt about their cancer care preparedness post nursing school.

The informal interviews and survey convinced me there was indeed a need for more information, but the tight curriculum of the English nursing college I teach in struggles to accommodate more lecture time. The results of this study fostered the need for a handbook to provide additional information regarding cancer care. I developed The Cancer Caregiver Handbook for nursing students and new graduates alike that is found in Part 2 of this document.

The ensuing Cancer Caregiver Handbook was designed to subsidize and enrich nursing students and practicing nurses alike, with the goal of helping them appreciate and understand those elements specific to the role of caring for and communicating with cancer patients. The Cancer Caregiver Handbook may also be beneficial to the lay person caring for someone with cancer, as the use of medical terminology is limited. It is my intention to emphasize and illustrate the importance of caring for the patient with cancer holistically and finally to point out

that caregivers themselves require attention as well, in order to ensure they are spared the stresses they might encounter when performing this altruistic act.

The following subjects are covered in The Cancer Caregiver Handbook:

- Knowledge in terms of the disease process, the treatment plan and its effects.
- The emotional toll which includes the emotional toll on all members involved.
- Do we talk about the diagnosis? How much do we say?
- Communication skills required to effectively help reduce stress and improve patient--family dynamics.
- Stress reduction strategies for patients and caregivers.
- IT (information technology)

Table of Contents

Chapter 1

Review of the Literature

Cancer nursing is in a dynamic state in many countries as workloads have changed in light of the sicker patients in hospital and home or community settings. This transformation results in an increasing amount of knowledge required to be an expert level nurse in keeping with the complexity of today's health care system (Tishleman et al., 2008). It is a most important contributing factor to nurses' education.

The majority of papers examined in the review of literature were related to the benefits of augmenting student's education to better prepare them while caring for cancer patients. The bulk of the studies are from the United States and Europe that have a different concept of health education than in Canada. The information is valid as there were underlying themes that were similar to both countries, such as the nursing curriculum, difficulty with communication and the importance of communication. I have focused on presenting articles that cover material that I have found to be absent from the college nursing program curriculum at John Abbott College.

Due to the prevalence of the disease, nurses of all disciplines will encounter increasing numbers of cancer patients thus emphasizing the need for specialized skills and knowledge in order to provide the complex care required to manage the medical, logistical, emotional, and psychosocial needs of this patient body. Many authors (Childress and Gorder, 2012; Hermann, Conner, & Mundt, 2008; McLennan, 2013; Tishleman, 2008) concluded that nursing schools should provide a broad foundation of knowledge as new graduates require the skill set to work in specialized areas such as oncology. It is important to note that in my experience and that of others (Charalambous and Kaite, 2013; Copp, Caldwell & Atwal, 2007; Hermann et al., 2008) hospitalized patients with cancer or a history of cancer are not restricted to oncology units. Due to the fact that there are so many new cancer cases each year, there are more patients in hospital with cancer and since the rate of survial has improved signifcantly in recent years, nurses find large numbers of cancer patients and survivors in numerous areas (Hermann et al., 2008). My final objective is to include cancer care knowledge in all appropriate classes thourought our three-year nursing program at John Abbott College.

1.1 The Need for Cancer Care Education

In a study of nurses working in a variety of settings, 81% of nurses had cared for cancer patients and 87% encountered patients with cancer for non-cancer-related problems (Mundt et al., 2005, as cited in Hermann et al., 2008). This particular study emphasized the need for all nurses to have current cancer care knowledge (Hermann et al., 2008). I agree that this is imperative in order to adequately prepare nursing students to meet the demands of the cancer patients they will find in all settings. Knowledge of prevention, detection and treatment is a necessary part of the nursing program curriculum. In addition, I have grasped from the studies in preparing this paper that there exists a lack of curriculum material to foster communication with cancer patients and the majority of nursing students are stymied when they are assigned to a cancer patient in the clinical setting.

A study of undergraduate students caring for cancer patients found the students were ill-prepared to care for them and to deal with death and dying (Charalambous & Kaite, 2013). During their clinical placements students were faced with cancer care and some students reported feeling “shattered in pieces” or “on an emotional rollercoaster.” Other students felt they were in an uncomfortable situation stating they felt “challenged and powerless.” Charalambous & Kaite (2013) identified the need for theoretical and experiential laboratories in the nursing program as well as debriefing time in the hospital setting. Practicing communication in the context of cancer patients would benefit the students.

All nurses have an important role to play in order to ease the adversities of illness that may be diagnosed as cancer on their unit, therefore students can benefit from sound knowledge in their nursing program when exposed to the experience of cancer care. In addition, nurses are required to be aware of the stressors that individuals and families may face on the continuum of the cancer journey and should promote healthy lifestyles to prevent the development of cancer in everyone they encounter.

1.2 The Curriculum

The task of nurse educators is great as they strive to foster nurses who can break down barriers and are sensitive, supportive and empathic with their patients (Purnell, Walsh, & Milone, 2004). Teachers would need to provide feedback and support them in communication techniques. The curriculum would need to reflect the growing need for cancer care knowledge as well.

Of the research I reviewed, the most interesting article on nursing curriculum was by Purnell et al. (2004) because it explained Carper's framework (Carper, 1978, as cited in Purnell et al., 2004), the fundamental patterns of knowing. Carper described the following four types of "knowing": "Empiric knowing" which refers to facts and science; "Personal knowing" which implies recognizing the patient as a whole person within an authentic personal relationship; "Ethical knowing" which involves complex cultural values when deciding what ought to be done; and "Aesthetic knowing" which is an understanding or appreciation known as "the art of nursing." Purnell et al. (2004) posited that this framework helps us understand ways in which nurses can know their practice and when used as a teaching tool it can be implemented by nursing faculty to help students better understand and "appreciate the issues of patients and families in oncology care" (p. 305).

The goal in the study by Purnell et al. (2004) was to look at ways to engage students when caring for persons with serious illness, helping them appreciate what it would be like to live with the illness. They sought to have students see the patients differently than someone needing to be cured but rather someone who was growing "and fulfilling their human potential" irrespective of the diagnosis. In doing so, the student was required to know about human behaviour in illness, thus the course was designed to include an understanding of self, the patient and the patient's family.

Purnell et al.'s study involved 30 students who first used and then identified the most helpful activities in their cancer course. I referred to this study when planning the sections of the Cancer Caregiver Handbook deciding to concentrate on knowledge of the disease, holistic care of the patient and family, and communication. The nursing curriculum at John Abbott College addresses all types of knowing as described by Purnell et al. (2004) but with respect to cancer care, I believe there is an increased need for empirical knowledge and communication specific to cancer care. From the results of the survey I trust the following activity that was explained in their study (Purnell et al., 2004) would benefit our students:

Of all the activities the students applied in the study they rated the cancer survivor interview assignment as the most helpful in terms of connecting with cancer patients and their families (Purnell et al., 2004). The students were required to take thirty minutes to an hour to interview the patient. Some examples of the interview questions were: "What have you learned as a result of your illness? What are your greatest strengths? What is your philosophy for getting through the rough times? What do you want to accomplish most in your life now?"

(Purnell et al., 2004, p. 305). The students indicated they enjoyed and valued the assignment, learned so much, and found they should not shy away from talking about these challenges. They learned how to listen and respect the patient. Learning what to say to the cancer patient is necessary as it is very difficult to grasp without preparation. Spirituality was another subject the students had to engage their patients in, asking questions about hope, goals, emotional, physical, and spiritual support. Incorporating this activity in our program would be a valuable exercise.

The researchers found that implementing these activities emphasized the importance of holistic care of the oncology patient, helping student nurses to develop empathy and caring sensitivity towards their patients. They also noted the students had a new perspective of oncology nursing: “Patients were not dying–they were living!” (Purnell et al., 2004, p. 308).

The University of Louisville School of Nursing implemented the cancer-nursing Faculty Fellows Progam in order to enhance the knowledge of faculty in cancer care and subsequently enrich the nursing students knowlege with the goal to provide quality care to cancer patients. A four-week program covered cancer prevention to end-of-life care using research that was cutting edge including public health, genetics, and interdisciplinary care. Based on the “Statement on the Scope and Standards of Oncology Nursing Practice,” the program integreated cancer care throughout the Nursing program curriculum (Hermann et al. 2008).

O'Connor & Fitzsimmons (2006) provided suggestions as to what cancer nursing content should be included in the undergraduate preregistration curriculum and highlighted an example of providing such a curriculum within the basic training of nurses which matches our program content.

The idea that further studies are required to appreciate what specific needs there are in order to prepare health care professionals to work with cancer patients were expressed by Copp et al., (2007). The authors noted a lack of sufficient classroom input and stated this is an area which requires attention as it has been largely ignored to date.

1.3 The Effects of Cancer on Family Members

Many studies looked at the effects of cancer on family members and providing care was often depicted as very stressful particularly because of the association of cancer with high mortality. Lewis (2006) stated that most studies were focused on short-term survivors and breast cancer. They concurred that family members become stressed when a member has cancer and the members have trouble supporting each other and the functioning of family members is disrupted when one of them is a long term survivor.

In addition to this fact, the findings of Stenberg, Ruland, Olsson, and Ekstedt (2012), found that family caregivers (FCs) are usually relied on as the primary source of social and emotional support for patients and are required to be responsibile for daily functioning in the family. Their study involved interviews with 15 FCs and they identified the following main themes: uncertainty, added responsibility, altered social life, greater closeness, balancing problems and needs, caught between known and unknown, and feeling helpless yet requireing competency. It illustrated that “emotions and burdens vary over time, back and forth in the process of caregiving, parallel to the patients illness ” (p. 922).

A similar report by Murray et al. (2010) stated that FCs go through different emotions than those of the patient, affecting the psychological well being of both. Other studies agree with this claiming FCs experience fear, uncertainty, helplessness, powerlessness, and a lack of control (Houldin, 2007, as cited in Stenberg et al., 2012; Northfield & Nebauer, 2010).

Authors Murray et al. (2010) reinforced what others have stated (Gaugler, 2009; Lewis, 2006; Shin et al., 2011; Swanberg, 2006), that patients are in hospital for a shorter time and many cope with long term illness at home subsequently placing a burden on the caregiver. To conteract the increased load on the family, the following studies provide ideas to support the caregiver which in turn helps the patient as well. Swanberg (2006) suggested involving a social worker to help negotiate time away from work or extra help for the employed caregiver.

It is very important that family caregivers are included in the information about the diagnosis, treatment options, and side effects as being informed helps to reduce the stress and burden placed on the caregivers (Nijboer et al., 1998; Yates & Stetz, 1999; as cited in Carter, 2001). As mentioned previously, patients are being sent home earlier and caregivers require information to alleviate homecare stress. Contrasting this view, Carter's (2001) study involving 21 female family caregivers found that when caregivers were given more news about the illness than the patient was given, they were worried about what the patient should know. This became an additional strain on the caregivers, possibly isolating them from the patient. The nurse needs to understand the communication dynamics of the dyad and offer support while being attentive to the individual needs of patients and caregivers.

I found the results of a study on disease awareness involving 212 cancer patient-caregiver dyads interesting because the patients with incomplete knowledge of their disease had improved health related quality of life (QOL) but their caregivers found the lack of knowledge to be a burden, particularly on their emotional health related QOL (Papadopoulos et al., 2011). The authors pointed out that a holistic approach is necessary for the patient and note that caregivers require mental and physical assistance as well. Including caregiver needs is an essential part of the nursing curriculum. One can conclude there is sufficient evidence that the responsibility of caring for cancer patients at home falls on the shoulders of family members (Gaugler et al., 2005, 2008, 2009) and this may lead to negative emotional, social and psychological health outcomes in the caregivers (Given et al., 2003, Haley et al., 2003, Nijboer, 1998, & Pitceathly et al., 2003 as cited in Gaugler, 2009).

Research shows that caregivers are often spouses of the patient and they tend to neglect their own mental health. This was confirmed in a study of 75 caregivers who were given a comprehensive needs assessment which listed 67 potential problems in QOL as caregiver, and 9 information needs items. Results revealed the top 20 needs reported by caregivers were those of fear and emotional burden adding that they expressed a desire for more support for symptom management and coordination of services (Osse, Myrra, Schade, & Richard, 2006). Kim, Schulz, and Carver (2007) found that spouses have a greater burden as they have a dual role as a primary attachment figure and caregiver. Nursing teachers must teach the students to consider assessment of partners in keeping with the plan of holistic care. Students need to know that communication can shut down and that social workers need to be involved when necessary.

Lewis (2006) studied the effects on family members of long-term cancer survivors focusing on the ill parent as caregiver. Although parents are aware that illness of a parent affects children, most expressed they were struggling with their own fatigue or illness and didn’t know what to say to their children. Younger children and adolescents reported that no one helped them cope and that they did not want to talk about it for fear of placing more burden on the ill parent (Lewis, 2006). Whereas mothers of school age children found they weren’t able to be the parent they wanted to be, particularly during their treatments, spouses had difficulty knowing how to support their wives and knowing what to say. Gaugler (2009) added that most family members found that they did not have the skills or confidence to support each other.

The difficulty surrounding couples is that the demands on each of them result in less time to focus on each other’s needs and feelings, or seek cancer support needs (Lewis, 2006). It is up to health care professionals to help educate couples in terms of what to expect and to keep the lines of communication open including a discussion surrounding sexuality. This can help to improve dialogue between partners allowing them to discuss the issues together and help to avoid relationship problems (Gilbert, Ussher, & Perz, 2010). The benefit of opening the sexuality topic has been documented in studies but few health care professionals engage in these sensitive discussions (Stead et al., 2002 as cited in Gilbert et al, 2010). Role playing with student nurses could increase their comfort level.

1.4 Caregiver Needs: Psychological Assessment

In light of the fact that the five-year survival rate for all cancers has improved (Canadian Cancer Society, 2013) there is still a perception by most people that cancer is a life-threatening disease and hearing this diagnosis is a source of great stress to both patients and families.

Literature supports the belief that family members caring for a chronically ill person are at risk for physical and emotional problems that can be linked to poor health outcomes including possible sleep problems, increased anxiety, and depression (Shin et al., 2011). In addition it has been documented that difficulty with work and financial burdens can have a negative impact on caregivers QOL.

Because the implications of the disease impact the patient and the caregiver, the World Health Organization and others (Papadopoulous et al., 2011) recommend approaching patients and caregivers together as a unit (WHO, 2013). We teach the “whole” family holistic care approach.

Shin et al. (2011) developed a needs assessment tool for caregivers of cancer (CNAT--C) patients. One of the advantages of a needs assessment over a QOL evaluation is that the caregivers can identify their own needs and health care providers can direct them towards appropriate professional care. Assessment and intervention is crucial as noted in the study by Hodges, Humphris & McFarlane (2005) determining that early intervention with the patient and caregiver helped to prevent the onset of psychological distress in both members. They found that in some couples there was little evidence of psychological distress while other couples were more vulnerable and at a higher risk. It was posited that it could be that some dyads communicate distress between themselves however the study gave no reason for cause and effect (Hodges et al., 2005). Once again I would propose to our students that the first step the nurse should undertake would be a proper assessment to identify those at risk, both the patients and the caregivers.

Whereas many studies focused on the negative outcomes, some studies have shown that family members can find positive aspects of the challenge, such as personal growth or positive change, becoming more empathic, and appreciating new relationships (Kim et al. 2007). The authors' findings were mixed in terms of what could be considered beneficial and what was detrimental but they concluded that caregivers could benefit from learning how to accept the situation and find meaning in the experience. This is a good message to share with our students.

1.5 Emotional Stress for Caregiver Partners

It is common knowledge that caregivers are known to neglect themselves and as a result their physical well-being can be compromised because of forgetting to eat, not sleeping enough and skipping exercise. In addition, caregivers may also neglect their mental health (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). The authors of this study involving 200 primary caregivers for patients with advanced cancer concluded that most caregivers are spouses of the patient and that many suffered from major depressive disorder, post traumatic stress disorder (PTSD), general anxiety disorder or panic disorder. Some caregivers are asked to perform tasks that they are not comfortable with and need to know that a nurse can come to their home to teach them how to perform these tasks (Vanderwerker et al., 2005). There is much patient teaching involved to alleviate some of the stressors.

Cipolletta, Shams, Tonello, and Pruneddu (2013), define three types of caregivers with different levels of anxiety resulting from how much support they had and how much others relied on them. They postulated that varied types of support were required depending on the individual circumstance.

When undergoing active treatment there are measures that can be introduced to patients to help them cope with adverse side effects. These practices may serve to lower the caregiver's stress level indirectly. Student nurses should be alert to the signs of cancer related PTSD and if it is suspected, patients can be taught skills to reduce the likelihood of getting PTSD. Other methods that benefit patients are psychotherapy, psychoeducation and stress reducing medication. Early intervention can improve the adaptability and recovery and foster a better QOL during treatment and post treatment. Relaxation, guided imagery, controlled breathing and distraction techniques are suggested (Kangas, Henry & Bryant, as cited by French-Rosas et al., 2011).

1.6 Communication

As previously discussed in section 1.3 (The Effects of Cancer on Family Members), good communication skills are an asset for all patient caregiver relationships. Learning proper assessment is imperative for nurses. A tool to evaluate communication was developed by Siminoff, Zyzanski, Rose and Zhang (2008). Their Cancer Communication Assessment Tool for Patients' and Families (CCAT-PF) was used to evaluate levels and types of communication between caregivers and patients. The study sample consisted of 190 pairs of patients with lung cancer and their families. The authors noted that although some families assume the responsibilities as caregiver without difficulty “others lack social, emotional and economic resources to do so” (Cameron et al., 2002, Fairclough et al., 2000; Given & Kozachik, 2000; Rabow et al., 2004 as cited in Siminoff et al., 2008). Siminoff (2008) noted that research confirms being able to express ones emotions and share information leads to better psychological well-being. Failing to discuss the experience can have negative consequences for mental health as identified in five studies cited by Siminoff (2008), who stated the quality of communication “is a strong predictor of adjustment to cancer and caregiving burden” (p. 1217). Outcomes of several studies cited by Siminoff (2008) claimed that good patient–caregiver communication had a positive effect on pain management, decision making, and it resulted in fewer conflicts between family and physician.

When nursing students were reflecting on the most difficult task they had when communicating with cancer patients, one stated that starting the conversation and keeping it going was the most challenging (Kav, Citak, Akman & Erdemir, 2013). Some found it difficult to relate to the families and they were afraid of saying the wrong thing, while another student was fearful of letting her emotions show (Kav et al., 2013). The same thing can be said of our third year students who reiterated these sentiments during the informal talks I had with many of them.

Teaching nursing students empathic communication skills requires practice hence McMillan & Shannon (2011) suggested the students be exposed to situations in which they will develop empathic communication. The authors encouraged the use of improved teaching methods and evidence-based studies on the benefits of empathic communication. They stipulated that it is important to include patient and family input when evaluating the student as feedback from significant others is valuable. Communication techniques are part of every nursing curriculum but it is my feeling that techniques specific to cancer care would enhance the program. My preferred method of teaching communication is role playing. I would provide conversation leads for the students and they would act out the scenarios.

1.7 Information technology (IT)

Although it is empowering, as caregivers are searching on line for information about caring for their loved ones, Celene (2002) advised that it is important to use reputable sources. As a patient advocate the nurse can suggest sites or seek help from a reference librarian for up to date information. Celene (2002) added there are good Internet sites with online support groups as well that are available to talk about individual situations and exchange information about caregiving. There is a list of suitable support groups in Appendix A.

Chapter 2

The Survey

As a college nursing teacher, I noticed students encountered difficulties on many levels when caring for cancer patients. My main observations indicated there was a lack of confidence in communication as well as a lack of general knowledge regarding the disease and treatment. I gleaned information while observing students in their second year of nursing during their clinical stage on a medical oncology floor and while conducting informal interviews with third year students and new graduates of collegial studies in Nursing. Feedback indicated there was general unease felt when relating to and caring for cancer patients in the hospital particularly due to a lack of communication skills. As a result of talking with the students I created a questionnaire to get more information from practicing nurses in Oncology units. This survey was an attempt to highlight the areas of cancer care information that required enhancement in the nursing curriculum. A cohort of 18 practicing nurses comprised the study sample.

2.1 Method

A10-question self-reporting survey was developed to pinpoint the specific areas the nurses and certified practicing nurses (CPN) might identify as lacking in their nursing program. The survey was conducted in English and was emailed to the nurses by their significant head nurses. Data was collected from the self-reporting questionnaire six weeks after it was sent out using Survey Monkey (US).

2.1 .1 Participants.

The target population of this survey was 35 nurses employed as Certified Practicing Nurses (CPNs), Registered Nurses (RNs), or Nurses with a Baccalaureate degree (BScNs and BNs). There were a total of 19 respondents from Oncology units in one of two teaching hospitals in Montreal--The Montreal General Hospital (MGH) and the Sir Mortimer B. Davis Jewish General Hospital of Montreal (JGH). The respondents had either a CEGEP diploma in nursing (*n* = 8, 57%) or an undergraduate degree in nursing (*n* = 6, 43%).

There were an additional seven students in their final semester at John Abbott College with whom I spoke to informally by chance meeting about their curriculum and cancer classes. This data was not recorded and is not included as it was meant to generate ideas for a survey. The sample was one of convenience. Permission to engage the nurses in the survey had the approval of the units through the Head Nurses in Oncology at the MGH and the JGH. The respondents were promised anonymity.

2.1.2 Materials.

The survey was drawn up and entered on Survey Monkey. It consisted of 10 questions.

Questions 1 (Current employment status) and 2 (Areas of work) were created to collect data on the area the participants were currently working or had previously worked in. The information from this data would provide insight regarding how much cancer care experience they had. Those with more experience would likely be more comfortable with cancer patient care. Question 3 (Describe education) asked respondents about their nursing education to find out if they had a CEGEP diploma or a university degree in Nursing. This question was meant to see if there was a difference in the programs in terms of preparedness. The responses to Question 4 (Preparedness for cancer care) were measured using a Likert scale. The question asked specifically about working with cancer patients and how well their respective institutions prepared them for this area of nursing. Question 5 (Areas of program requiring more information) had participants identify the area(s) they would have liked to have had more information on in their nursing program. This elicited data about the areas that needed more attention in the John Abbott Curriculum. In Question 6 (another Likert-scale question) and Question 7, the nurses were asked how much support they had in their workplace. This was to determine if they were supported as they may have felt unprepared to work on their unit. Question 8 was a demographic question about the length of time they had worked and their age, asked in order to exclude those participants who had graduated more than eight years ago. Question 9 was an open–ended question (What strategies would you suggest to new nursing graduates?) that was used to provide strategies for new graduates in their transition to an oncology floor. Finally, Question 10 asked the respondents to give suggestions on how to improve the nursing program in their college or university, obviously beneficial to planning a program handbook.

2.1.3 Procedures.

Two head nurses were contacted and given an explanation of the project stating that the purpose was to evaluate the John Abbott College Nursing curriculum regarding cancer care. It was indicated the survey was a component of a course the investigator was taking at McGill University. Upon consent from the head nurses, permission was granted to have them forward the survey to nurses employed on their respective units. An explanation of the survey was included in the email to the nurses stating the purpose for the survey along with a link to the survey. The survey was sent to 14 nurses at the MGH and 21 at the JGH in February 2013. The data were collected in March 2013. Participants were asked to either check a box or write a response. A copy of the survey can be found in Appendix B.

2.2 Results

Among the 18 nurses who responded there was a wide range of ages in the sample including four nurses between the ages of 51 and 60 who were excluded because of the number of years lapsed since graduation. Only participants that had completed their studies within the last eight years were included in order to obtain relevant data. This brought the final sample size to 14.

Question 1--Employment Status. Of the remaining 14 respondents 43% were working full time and 57 % were working part time. It was postulated that those working part-time might have felt less overwhelmed and answered more positively about their preparedness from CEGEP. The investigator was also interested in knowing how many were new CPNs and the results indicated that a combined 28% were CPNs working either part-time or full-time. This is relative because nurses with the least amount of time since graduation would likely yield more reliable data because these respondents would have had a better recollection of their nursing program curriculum than candidates who had graduated years later (see Table 1).

Question 2--Areas of practice. I was obligated to eliminate this question when interpreting the results due to the fact that there was an error in the program which did not allow the respondents to choose more than one box, resulting in worthless data.

The reason for this question was to determine if practicing in an oncology unit right after graduation influenced their level of comfort in a negative way as it might have made them feel overwhelmed from the beginning and caused them think they weren't adequately prepared in CEGEP. Those graduates who worked elsewhere prior to an oncology unit might have had an increased level of confidence and felt better prepared as a result of not having had as many or any cancer patients to attend to in their previous work experience (see Table 2).

Question 3--Education and Age. 57% of the respondents had CEGEP diplomas and 43% had university degrees. The main focus was the CEGEP (college-level) sample but comparing the two groups was interesting because the data from both groups indicated that they sought more information from their respective nursing programs.

With respect to age, the decision to limit the age or years of practice of the respondents was important because one of the excluded respondents answered “I don’t remember” to Question 4 (Preparedness for cancer care). Of the remaining participants, 8 were between the ages of 26 and 30 (57%), three were between the ages of 21 and 25 (21%), two were between the ages of 31 and 40 (14%), and there were no nurses between the ages of 41 and 50. One respondent was either 19 or 20 years old. Age group 31 to 40 became the cut-off point because no older nurses were in the sample. A majority sample between the ages 26 and 30 was positive because they would likely remember the content of their nursing program better than nurses between 31 and 40. The age and the years of experience do not correlate because a nurse in the age bracket of 31 to 40 had only been working for 3 months (see Table 3).

Question 4--Preparedness for Cancer Care. This question along with Question 5 were the most telling because the intent to obtain data about the preparedness of newer graduates and needed to find out what information they would like to have had more of in their programs. Only one respondent chose “very prepared” (7%), five indicated they were “prepared” (36%) and 8 chose “somewhat prepared” (57%). This shows that more than half could not state they were either “very prepared” or “prepared” and gives the impression the program could do more to prepare the students to care for cancer patients. See Table 4.

Question 5--Areas Requiring Additional Information. The areas the nurses reported to have received inadequate information about in their programs of study were communication, disease process and treatment side effects, loss and death, and stress reduction. The greatest percentage of respondents (64%) chose communication, recognizing patient and caregiver needs (stress related), and coping with loss and death. The next most important items chosen (57%) were disease process, learning to reduce stress in self or others, and side effects /management of treatment. Half the respondents chose chemotherapy and radiation therapy.

It is reassuring that the nurses are concerned with recognizing caregiver and patient stress related needs (64%) because they are considerate of others and want to know how to help them. The concern is whether or not they have had enough information about recognizing nursing stress related needs and wonder if they are putting themselves in harm's way. Fewer than half (43%) identified this as an area requiring more information, leading to the suspicion that they might not have been taught enough about how to avoid problems that may lead to burnout or compassion fatigue.

All responses were very valuable because they contextualized the decision as to what information should be included in the Cancer Caregiver Handbook. The areas receiving the least importance were: causes of cancer, biological therapy, alternative therapies, and assisting the caregiver (family/friend). The causes of cancer and alternative therapies are emphasized in the nursing program at John Abbott College (see Table 5).

Question 6--Workplace Support. Four respondents (26%) strongly agreed with the statement "I felt supported in my current workplace when I started" and 9 (64%) agreed with the above statement, for a total of (90%). Only one (7%) respondent disagreed with it. It was encouraging to see that most of the respondents felt good support was provided which helps reduce the incidence of caregiver stress or burnout (see Table 6).

Question 7--Methods of workplace support. Question 7 provided information as to what tools were in place in order to supply information and support to their nurses. Ten respondents (71%) reported there were in-services to educate the nurses. This was another encouraging finding as continued education after graduation would likely aid those that felt their curriculum hadn't prepared them adequately, affording them the ability to gain confidence from the additional information they received on their units. It was discouraging however to note that only half reported there were meetings to support them. It may have been better to rephrase this question to find out if there were individual meetings to assess the stress level and how each of the nurses were coping on the unit. The structured orientation program is in keeping with most hospital units and very beneficial. Knowing there was accessible assistance from the nurse manger or resource nurse was pleasing to see because 11(79%) responded positively to the availability of this method of support (see Table 7).

Question 8--Months/years worked as a nurse and in Oncology. This question was beneficial as it provided data that was needed in order to exclude respondents who had worked more than eight years after graduating. Four subjects (22%) were excluded from the sample. The second part of the question that referred to the length of time worked in Oncology provided insight on whether or not the length of time in Oncology influenced their answers regarding preparedness. There was no correlation between the length of time in Oncology and preparedness (see Table 8).

In addition to the data for Question 8, the datum was compiled for preparedness between university educated nurses and college educated nurses to see if there was a difference between the two. Of the 6 university graduates, 1 stated they felt *very prepared* (17 %), 2 stated they felt *prepared* (33%), and 3 stated they felt they were *somewhat prepared* (50%).

Of the eight college graduates three (37%) stated they felt *prepared* and the remaining five (63%) stated they felt *somewhat prepared.* This revealed that there was a greater percentage of college graduates that felt they were *somewhat prepared* compared to the university graduates (50%). Three (38%) of the college students stated they were *prepared* however one university graduate of the two groups stated they were *very prepared*. Hypothetically speaking adding that value to the *prepared* value would bring the *prepared* value to 50% indicating the university graduates scored higher in the *prepared* category and lower in the *somewhat prepared* category. Of these results one can conclude the highest number of responses for both groups was in the *somewhat prepared* category indicating that more preparedness in both educational institutions is warranted (see Table 9).

Question 10--Suggested strategies for new nurses. Nurses responded as expected advising new nurses to do their own research and be knowledgeable about cancer and to look at the "whole patient" ensuring "comfort, communication and empathy". One person wrote that strong communication and having a deeper understanding of cancer was necessary. They were picking up on the same needs I singled out in the introduction. Another said the first few months were challenging and it would be a good idea to identify your own strengths and weaknesses, and use coping methods to get through hard times. Having a healthy lifestyle and exercising was advocated by one respondent. I tend to agree with that statement as I believe exercise and creating time for yourself are good coping mechanisms to have in place (see Table 10).

Question 11--Suggestions to improve the nursing program. The bulk of feedback centered on not enough time spent on cancer as an illness and communication. They would like to see more cancer classes added and a lab day with a focus on oncology. All of these are great ideas that I would like to see implemented. Another area of interest in terms of more class time is end-of- life communication classes. One respondent stated that you really need to interact with the clients to understand the work involved in their care. Communication takes practice and it seems they are aware of this factor (see Table 11).

2.3 Discussion

2.3.1 Conclusion.

The study examined a variety of characteristics including comfort level with cancer patients, nursing program curriculum, stress in the workplace, and demographic factors. Overall findings in terms of preparedness have led to the conclusion that the college curriculum needs to be altered in order to provide additional information on the subject of cancer care. One would question if colleges and universities are doing an adequate job in preparing nurses to care for cancer patients when they enter the profession. The literature pointed out that there are increasing numbers of cancer patients in all hospital units, and sheds light on the fact that nursing graduates felt ill-prepared when faced with patients that have a history of cancer or an active cancer diagnosis.

The survey gave insight into the areas the nurses felt were lacking in the nursing program. Congruent with the literature, the survey pointed to communication as an area that required attention as well as information about the disease process, side effects of the disease and treatment modalities. In this study the majority of nurses singled out the need for more information about the most common treatment modalities: chemotherapy and radiation therapy.

The findings suggest that it would be in the best interest of colleges to further investigate the knowledge level graduates have surrounding preventing compassion fatigue and caregiver burnout. Contrary to literature most of the respondents did not identify the need for preventing burnout or practicing stress management. The in-services are helpful and serve to reinforce knowledge however preparing the nurses well in advance is most advantageous. The assessment and planning of an improved college curriculum is warranted.

2.3.2 Limitations.

Clearly the sample size is cause for concern as it is small. The delay in the time between completing college and taking the survey is a limitation because the study relies in part on memory. Too long a delay will hinder the accuracy of the responses as the nurse cannot remember the details of subjects covered in their program. It would have been better to ask for the exact age of the respondents because the age group of 31 to 40 is large and there was no way of knowing if the two nurses in that group who worked three months and eight years were closer to age 31 or age 40. It would have been preferable to have a cut off point of one or two years post-graduation. Also, asking how many years they had worked since they graduated would have been more beneficial as some may have had children and then taken maternity leave for some years. Data indicating where they attended college of university would have been helpful as they may not have been from Quebec.

2.3.3 **Considerations for future studies.**

It would be worthwhile repeating this study with a larger cohort of college nursing graduates and it would be useful to include English- and French-language CEGEP students. Further studies could include university-level graduates for comparison.

Collecting data on the number of hours devoted to cancer care in the various educational institutions would provide valuable information prior to beginning a study. Would there be a correlation between the number of hours spent on cancer care in the nursing program and increased knowledge and comfort levels of cancer care in the unit? It would be worthwhile to investigate this question. Gathering data from more oncology units and other units would have been an improvement by providing more varied data. Having a sample of convenience should not interfere with the results but a random sample is preferable.

More questions about communication techniques employed by nurses would be another avenue that could provide data to help improve the nursing curriculum. Tracking stress levels using a Likert scale as the nurses transition from the classroom to the cancer unit would be another valuable area of study because burnout is prevalent in nursing due to nursing staff shortages and sicker patients.

The length of time between graduation and years practiced would be best if cut off at one or two years to obtain more reliable data.

The above information would serve to provide recommendations to colleges and universities that have nursing programs and to hospital units that treat patients with or without a cancer diagnosis as any individual can become a cancer patient at any time.

The Cancer Caregiver Handbook

Introduction

“Whether the disease is cured, in remission, under control, or progressing, we have the privilege of watching our patients do everyday things heroically; we gain an appreciation of them and how they get the most out of living” (Winningham, 1995, as cited in Barnett, 2001, p. 787).

When one is in the role of caregiver as a nurse, nursing student, partner, family member, or friend, there are elements that require knowledge and understanding in order to improve your confidence and well-being while providing physical and emotional support, empathy and compassion to your cancer patient. There is an overwhelming amount of information on this subject and it can be daunting when one is considering what to learn about cancer itself and about caring for someone with cancer.

Knowledge is power and it is my belief that it is the key to the beginning of a successful cancer patient-caregiver relationship. With this relationship in mind, the focus of this educational tool is to gain insight and understanding of the components that relate to caring not only for our cancer patients, but for *ourselves* as caregivers.

Current datum from the Canadian Cancer Society (2013) inform us that cancer is the leading cause of death in Canada and is responsible for about 30% of all deaths. It is estimated that in 2013, there will be 187,600 new cases of cancer and there will be 75,500 deaths due to cancer in Canada. There are approximately 5,000 more cases in men than women. The number of new cases does not include 81,700 new non-melanoma skin cancer cases (Canadian Cancer Society, 2013).

- On average, over 500 Canadians will be diagnosed with cancer every day.

- On average, over 200 Canadians will die from cancer every day (Canadian Cancer Society, 2013).

Although many associate cancer with death there is a need to educate the public that there are more cancer survivors now than there were in previous years, for example, the five-year relative survival rate is high for prostate cancer (96%) and breast cancer (88%) (Canadian Cancer Society, 2013). The incidence of cancer increases with age, specifically after the age of 55 in both men and women (Geffen, 2010). The population most effected with new cases and related deaths are those over the age of 70, however better screening methods and treatment means that more than half will survive. The earliest of the “baby boom” generation who were born between 1946 and 1964, will be reaching the age of 70 in a few years. Improvement in cancer survival rates has meant that people are living with the disease longer and receiving successful outpatient treatment.

The impact of the disease spreads beyond the individual to the caregiver, family, workplace, and community, and will be a burden to many as the “baby boom” generation reach the age of 55 (Geffen, 2010). One must not overlook this impact on the nurse or caregiver themselves which can be daunting. Cancer may still result in functional dependence and negative mental health among persons receiving successful outpatient treatment (Stanton, 2006). Current research highlights the incidence of secondary traumatic stress (STS) as a repercussion from caring for people who have experienced trauma (Quinal, Harford, & Rutledge, 2009).

The role as a nurse in oncology encompasses sensitivity, empathy, compassion, and knowledge regarding the illness and its course, as well as treatment options including alternative therapies available to patients (Alfes, 2011; Carroll-Johnson, 2010). Nurses in oncology require excellent people skills and the availability of mentors with whom they can share their feelings (Carroll-Johnson, 2010).

Table of Contents

Chapter 1

Cancer and Treatment Modalities

1.1 The Disease Process

Uncontrolled and unregulated growth of cells describes more than 200 diseases referred to as cancer. The mutated cells can survive, become malignant, and invade surrounding tissue. There is a common belief that cancer cells divide more rapidly than normal cells however this is not the case. The cells double with each division and do not stop dividing as a normal cell might do. Our immune system can tell the difference between normal and abnormal cells but due to the fact that some cancer cells evolve from "normal" cells, the immune response may not be efficient enough to destroy them. There are antigens on the cancer cell surface that help lymphocytes identify and destroy them, but somehow these cells can evade the mechanism of destruction of immune systems antibodies (Bender & Rosenzweig, 2010). These cells form a mass referred to as a malignant tumour.

Progression occurs when the tumour increases in growth rate and spreads to a distant site (metastasis). The classification of tumours depends on where they are in the body, how different the cells are from normal cells (grades I – IV), and the spread of the disease or "staging" (0 – 1V). Finally the TNM classification system defines the extent of the disease process by tumour size (T), spread to regional lymph nodes (N) and metastasis (M).

1.2 The Causes

People often ask themselves if there was something they could have done to avoid getting cancer. It is known that cancer may be caused by chemicals, radiation, viruses and damaged DNA. The WHO identified more than 100 chemical, physical, and biological carcinogens in 2012. In some cases cancer may be hereditary. Persons of all ethnic groups and all ages can get cancer and the inability to pinpoint what exactly caused it is upsetting for many people because having a reason for something helps us understand and begin to come to terms with it. Nurses have a key role to play in cancer prevention as the common risk factors are modifiable including tobacco use, excess body weight, sedentary lifestyle, unhealthy eating habits and sun exposure (Bender & Rosenzweig, 2010).

Teaching the public how to prevent cancer by adhering to a healthy lifestyle, and eating a balanced diet containing fresh fruit and vegetables, omega-3 fatty acids, fiber, reduced cholesterol and saturated fats is important. Partaking in mild to moderate exercise for 30 minutes five times a week, keeping a healthy body weight, and limiting alcohol consumption to one or two drinks a day is advised. Learning to detect tumours by performing breast self-examination and testicular self-examination and following screening guidelines is recommended. Nurses can educate the public to know the Seven Warning Signs of Cancer. Some other risk factors for cancer are chemical carcinogens, radiation, viruses, and genetic links.

1.3 The Treatment Plan and its Effects

To collaborate fully with the patient and family the nurse must be aware of the treatment plan and goals, whether it is to cure or control the disease. The four methods of treatment used today are surgery, chemotherapy, radiation and biological therapy each of which may be used alone or in combination. Some patients may enter a clinical trial which involves the use of a new treatment that has shown to be successful in the laboratory and is being evaluated for the first time in human beings. If this is the case the client is provided with information surrounding the effectiveness and side effects including the potential risks and benefits of entering the study. The client needs to know they can refuse to enter or leave the study at any time.

In order to fully appreciate cancer care it is important to reflect on the transformation that has taken place in cancer care over time. Today, more health professionals are taking an approach that encompasses the "whole person" as they seek an understanding and a holistic treatment that is integrative and compassionate. Increasing numbers of people are exploring the use of complementary and alternative medicines (CAM) and accessing information through the internet which has changed the way the health care system operates as integrative medicine and oncology fields emerge (Geffen, 2010). Geffen, (2010) described "Seven Levels of Healing" a term he has coined to educate and support patients, support persons and health professionals.

1.4 Surgical Therapy

The oldest method of treating cancer was to remove the tumour and this method is still effective as long as the tumour has not spread to other areas of the body. During some surgical cases the borders around the tumour will be examined microscopically to ensure the tissue beyond the tumour has no sign of cancer cells. The goal is to remove only enough tissue as necessary. If it is difficult to remove the tumour entirely, for example if it is attached to a vital organ, chemotherapy or radiation therapy may be used as well. Depending on the area of surgery, it may be the case that after surgery the client requires a feeding tube, colostomy (resection involving the colon) or a cystostomy (surgical opening into the bladder). These measures may be permanent or temporary. Surgery is also used to relieve symptoms of pain or pressure in cancer patients that are palliative.

1.5 Chemotherapy

Chemotherapy is a choice of treatment with a goal of curing or controlling the cancer and in some cases it is used to reduce unwanted symptoms in palliative care patients. All cells reproduce by dividing and multiplying while going through stages of active cell division and rest. Some types of chemotherapy are specific to certain phases of cell division (cell cycle phase-specific) and some are not (cell cycle phase non-specific). This means that some drugs may be more effective during certain cell cycles or there may be no difference at all. A goal of chemotherapy then, may be to target the cell during specific cycles, therefore in some cases, administering chemotherapy in combination may provoke a response to cells in different points of the cell cycle during division or rest. The effectiveness of chemotherapy depends on many factors including the speed of cell division, the tumour size, location and age, and the presence of resistant tumour cells.

Nurses who administer chemotherapy follow specific guidelines for safe handling as these drugs may pose an occupational hazard for any health care professional in contact with them if not careful. For the same reason clients or persons caring for the client, are taught to dispose of body fluids carefully such as flushing the toilet twice after use. Chemotherapy is administered orally or intravenously. The medication is considered a vesicant, which means it can be extremely irritating to blood vessels causing pain and extensive tissue damage if leaked accidentally into the skin. Nurses are taught to be alert to the symptoms of leakage (extravasation) such as pain, swelling, redness and vesicles on the skin which may lead to ulcerated tissue requiring closure with skin grafts. If patients experience difficulty during the insertion of the IV or are going to be having chemotherapy often and would like to reduce risks to veins they may opt for a central vascular access device (CVAD) which comprises a catheter placed under the skin that feeds into a larger vessel. It can be used to take blood samples as well, because patients receiving chemotherapy always require a blood test prior to their treatment. Two other types of ports available are peripherally inserted central catheters (PICC) and implanted infusion ports (port-o-cath or POC). Complications of these devices are blockage and infection.

1.6 Radiation Therapy

Radiation therapy is a local treatment that targets the cancer cells directly using energy that ionizes and excites the cells breaking the chemical bonds of DNA resulting in cell death. Normal cells repair faster than cancer cells therefore cumulative doses will damage the more vulnerable cancer cells leaving the normal cells more chance to recover. Radiation may be administered externally (external beam) or internally (brachytherapy). The former method is the most commonly used whereby the client is exposed to a megavoltage of radiation typically from the cobalt 60 machine. The latter method consists of implanted radioactive materials directly into the tumour or close by, either temporarily or permanently such as when using radioactive seeds. Clients receiving radiation are monitored for cumulative radiation amounts as there are limits to exposure, and nurses administering radiation wear devices to tally their radiation exposure. As with chemotherapy, the goals are cure, control and palliation. In some cases the tumour may be radiated for shrinkage, to facilitate surgical resection, or when a tumour is inoperable. Palliative use is to control symptoms of the disease such as pain, obstruction or bleeding.

1.7 Biological Therapy

Interferons (IFNs), interleukins (IL), monoclonal antibodies (mAbs) and growth factors are known as biological agents. These are used alone or in combination with the other modalities of cancer treatment mentioned above, and affect the tumour by either killing it, improving the immune system of the host, or by interfering with the cancer cells' ability to reproduce. The benefit to the patient is that cancer cells can be killed without damaging normal cells. The most common side effects of IFN's are flu-like symptoms. MAbs have been used with patients that have a specific antigen on their lymphocytes.

1.8 Bone Marrow and Stem Cell Transplantation

The function of bone marrow is to produce new blood cells. Bone marrow differs from peripheral blood in that it contains more stem cells which are able to produce or grow new blood cells. Clients undergoing bone marrow transplantation (BMT) may have malignant or non-malignant disease and the goal is curative. Although cure is not always possible, the client usually has a period of remission. The idea is to find a donor that matches (allogeneic), or to remove bone marrow from the patient prior to treatment (autologous) in order to be able to replenish their bone marrow and resume the function of producing new blood cells after very high doses of chemotherapy or radiation have been administered and have depleted the supply.

Marrow is typically harvested from the iliac crest (pelvic bone), or sternum (breast bone). It only takes a few weeks for the donor to replace the marrow however it can take two to four weeks for the transplanted marrow to begin producing blood cells therefore isolation precautions are in order. As with any procedure there may be complications such as infection and graft-versus-host disease.

It is possible to increase stem cell production with growth factors, and then collect the peripheral blood by using a method similar to dialysis called leukapheresis, which isolates the stem cells. The stem cells may be frozen for reinfusion after intensive chemotherapy. Umbilical cord blood has a rich supply of stem cells and can be typed and matched for allogeneic transplants.

Chapter 2

Side Effects of Treatment

The side effects of radiation and chemotherapy are varied depending on the extent and type of treatment given but many are common and are expected such as fatigue or nausea and vomiting. The client needs to be educated to order to help them cope better and lessen the impact of the side effects.

2.1 Fatigue

Fatigue is reported in 70% to 100% of cancer patients. Of patients having undergone chemotherapy 80% to 99% report they have experienced fatigue. It is the most frequent and undertreated symptom (Barnett, 2007). Brought on by surgery, chemotherapy, radiation therapy, biotherapy, and bone marrow or stem cell transplant, the impact of fatigue is great as it can affect the way people function and think, their relationships, and their sense of well-being which includes quality of life (QOL) (Barnett, 2007).

Nurses can assist patients to manage fatigue by teaching clients to have good nutrition, adequate hydration, to balance rest and activity, and to rely on support persons for help so as to decrease anxiety and manage pain. Partaking in light physical activity can be beneficial for the client as it will promote sleep, a better appetite, less stress and fatigue. Generally speaking fatigue peaks about seven to 10 days after chemotherapy and improves by the next cycle of treatment. It may last about six months after treatment is finished and it may be classified as acute or chronic. Radiation therapy causes fatigue that gradually increases in severity as the treatment progresses with the exception of lung cancer patients that are responding well to treatments causing their airways to open up, lessening the fatigue.

Factors contributing to cancer fatigue may be a function of poor appetite, role changes and an altered QOL or loss of hope, and it can be overwhelming when deemed chronic because it is not always relieved by rest (Barnett, 2007). Mental demands are often great due to information overload surrounding the illness and treatment and withdrawing is a way of saving energy. Nurses need to assess the patient as fatigue and depression can be misinterpreted. It is necessary to identify and measure fatigue, determine its meaning to the patient in terms of coping, and to provide interventions for comfort along with strategies to alleviate it.

2.2 Anorexia

The most difficult of side effects is anorexia which peaks about a month after treatment begins therefore close monitoring is required to ensure the weight loss is not excessive. Teaching the client to eat small meals more often that contain high protein and high calories is necessary. Taking nutritional supplements may be advised, as well as involving a dietician.

2.3 Bone Marrow Suppression

Blood cells made in the bone marrow are depleted due to toxicity that occurs with many chemotherapy regimens as well as with radiation. White blood cells (WBCs) die within seven to 10 days, red blood cells (RBCs) in two to three months and platelets in two to three weeks. It is the responsibility of the nurse to be on the lookout for symptoms and to be aware of blood-test result, particularly neutrophils as these white blood cells are instrumental in fighting infections and without them the client is at risk for succumbing to life-threatening infections. Thrombocytopenia (low platelets) may result in bleeding or hemorrhage. Anemia can occur due to low RBC levels. Transfusions can be given to improve the latter two problems depending on severity however neutrophils must come back on their own over time. Injections are available to help speed the proliferation of neutrophils and RBCs in the bone marrow.

2.4 Skin Reactions

Chemotherapy and radiation attacks cells that are diving rapidly therefore cells in the body that divide rapidly are most affected such as the skin, hair follicles and nails. The palms of the hands or soles of the feet may be targeted and numbing can occur with some chemotherapy regimes. Radiation causes skin redness in the first 24 hours of treatment and is likely to cause reactions in areas of pressure or in skin folds. Dryness with itching or draining irritated skin can occur and hot or cold packs need to be avoided. Hair loss from most chemotherapy is expected and hair begins to grow three to four weeks after treatment ends. This is devastating for many individuals and needs to be discussed openly.

2.5 Gastrointestinal (GI) Tract

This area comprises the mucosal lining of the GI tract therefore the mouth, esophagus, and intestines are at risk. Oral care and frequent inspection is required and saline or special rinses are helpful. Radiation decreases saliva production with can lead to caries therefore teaching patients to drink small amounts often is recommended. Nonirritating foods as well as taking antifungals may be necessary. The intestines are extremely sensitive to radiation resulting in nausea, vomiting and diarrhea. Nurses administer antiemetics (antinausea medication) and dexamethasone (corticosteroid) prior to some chemotherapy medications to alleviate symptoms. Careful monitoring to prevent dehydration and alkalosis (depletion of acid) is required. Clients are advised to eat light meals prior to treatments and to seek help for poorly controlled nausea as anticipatory nausea and vomiting can develop. This means that just entering the treatment center can trigger a reaction by association. Nonirritating foods are also advocated as well as antispasmodics and antidiarrheals depending on bowel activity. Three or more bouts of diarrhea should be reported to the nurse.

2.6 Pulmonary Effects

Radiation takes its toll because there is nothing in the way to absorb the rays and some patients develop cough, fever, or night sweats. With certain chemotherapies the patient may experience pulmonary edema (fluid in the lungs), fibrosis (excess fibrous tissue) and pneumonitis (inflammation of lung tissue). This can be alarming to the client because they may think the cancer is getting worse if they are coughing more, however it may be due to the opening up of blocked passages with improvement noted later on.

2.7 Reproductive Effects

Teaching is important as reproduction may be affected therefore measures to shield organs or pre treatment harvesting of sperm or ova is considered and discussed with the clients.

Chapter 3

Complications of Cancer

3.1 Nutrition

The disease itself and the treatments can cause anorexia which affects the nutritional status because some patients may be subject to a significant loss of appetite and weight. Eating small meals and snacks and including foods high in protein and calories is recommended. Chemotherapy often causes nausea and vomiting. If nausea is ongoing anti-emetics are helpful when administered 30 minutes before meals. Another side effect due to chemotherapy is stomatitis (mouth sores) or oral infections causing alteration in the mucous membranes. Avoiding seasoning and acidic foods and consuming a high calorie bland diet may be indicated. Cold and frozen foods are usually well tolerated. Taste may change and some patients experience less taste or a metallic taste when eating red meats. Diminished saliva is possible as a side effect of radiation. Diarrhea can cause dehydration and needs to be monitored. Fatigue also impacts the appetite and needs to be identified and addressed early on.

The easiest way to maintain weight in a motivated client is through oral supplements. A dietary counsellor helps the patient feel more in control and better both emotionally and physically. Fat and muscle loss are indications of poor caloric intake and a dietician should be consulted for any patient who experiences a 5% weight loss because once the weight loss exceeds 4.5 kilograms it is difficult to maintain the nutritional status requiring supplements, or if not successful, enteral or parenteral nutrition (given intravenously).

3.2 Infection

As discussed previously, the immune system may be compromised by the destruction of WBCs, specifically neutrophils (neutropenia), therefore teaching regarding the risk of infection is very important. When a patient is immunocompromised it is important to emphasize that the patient avoids coming into contact with anyone who may be ill. Remember that any temperature of 38˚C or more needs to be addressed immediately due to the fact that if not treated quickly it can become life-threatening.

3.3 Oncologic Emergencies

Generally speaking an emergency is the result of a tumour that has blocked an organ or blood vessel. Superior vena cave syndrome is evident by swelling noted in the face, around the eyes, distended neck veins, headache and seizures. Radiation may be used to reduce the blockage. Spinal cord compression causes intense localized back pain that does not let up. There may be weakness or numbing and possibly a change in bowel or bladder function. Third space syndrome happens when fluid shifts from the blood vessels into the surrounding tissue. This affects blood pressure and must be addressed immediately.

3.4 Metabolic Emergencies

Ectopic hormones can be produced directly from the tumour resulting in antidiuretic hormone imbalance, hypercalcemia due to parathyroid hormone secretion, and tumour lysis syndrome as a result of cell destruction from chemotherapy (Mayo Clinic School of health Sciences (2013). The latter can lead to acute renal failure. Signs to look out for in the first 24 to 48 hours after chemotherapy are: hyperuricemia, hyperphosphatemia, hyperkalemia, and hypocalcemia (blood tests results). Pushing fluids and administering allopurinol (medication) is the primary treatment method used to avoid renal failure.

3.5 Infiltrative Emergencies

Carotid artery rupture**:** It is possible that the tumour can invade major organs such as the carotid artery. Direct pressure needs to be applied and the client needs immediate surgery to ligate the vessel. Cardiac Tamponade: Radiation to the chest can lead to fluid developing around the heart (pericardial sac) resulting in constriction of the pericardium. Immediate attention is required to remove the fluid and adjust vasopression.

3.6 Pain Management

Half of all patients in active treatment report moderate to severe pain while 80% with advanced cancer report the same (Swensen, 2007). Nurses are instrumental in pain management because they have an ongoing contact with the patient. They must act as an advocate for the patient by responding urgently to pain and by educating the patient and family about the importance of good pain management. In today's world with effective pain medication available there is no need for undertreatment of pain and the need for good pain assessment cannot be emphasized enough. There are pain specialists available to manage cancer patients with uncontrolled pain. Addiction to narcotics is unlikely unless the patient has a history of substance or alcohol abuse. Because the use of narcotics can lower the respiratory rate and alter the level of consciousness, patients are evaluated carefully. Laxatives are provided because narcotic pain medication may lead to constipation, a common side effect.

Every individual interprets pain differently and caregivers must respect that pain is whatever the patient says it is. Apart from pharmaceutical management there are various other techniques for pain management such as relaxation, distraction, imagery, music, humour, prayer, biofeedback and hypnosis. Nerve blocks and acupuncture are sometimes useful.

Chapter 4

The Emotional Toll

Apart from being a resource book to guide the user in understanding the essential elements that define cancer as a disease and assist in navigating the treatment plans available, one of the goals of this handbook is to provide quality care while ensuring the caregiver has an appreciation of the emotional and social interruptions that take place in the family unit. It is my intention to ensure that the caregiver avoids Secondary Traumatic Stress (STS) or compassion fatigue. Preventing burnout is paramount and tools are available to ensure that the caregiver finds strength and rewards in the caring role which is vital to so many people experiencing cancer.

Although challenging, this can be the most personally rewarding experience you will ever have. The diagnosis of a family member affects the emotional balance of all members in the family. Responsibilities are altered, and social activities may change. How the families organize, communicate and solve problems can determine their ability to recover. Support may come from extended family, neighbours, colleagues, counselors and friends. In the beginning there may be a psychological crisis bringing about a multitude of emotions. Afterward the patients try to make sense of the meaning of the illness.

4.1 Hearing the Diagnosis

News of a possible cancer diagnosis is a threat which leads to much anxiety for the person and those who are close to them because it can take time to receive conclusive reports from pathology studies resulting in fear of the unknown. Feelings of anger, fear and depression can ensue and it is at this time the nurse must communicate effectively and actively listen to the client’s fears. In the first few months after diagnosis the patient may attempt to address the meaning of illness and the changes that must be made along with the possibility that they may die.

The establishment of a therapeutic relationship with the client while paying special attention to the client's need for repetition, reinforcement and reassurance is important as well as clarifying information without giving false hope. Most health care workers will avoid giving information about the persons prognosis when it is unfavourable. This is because it is difficult to predict the length of survival since every individual responds differently. Statistical information is available on line and, if a patient really wants to know, she or he will ask the doctor outright.

A study involving 51 patients, 51 nurses and 50 doctors found that most patients want to know the news whether good or bad and they also want to know what is in store in terms of tests, treament options and prognosis (Rassin. Levy, Schwartz, & Silner, 2006). When first hearing the news, they may be in shock, and due to anxiety, they often forget some of what they were told therefore they seek validation from nurses, particularly if they did not understand all the terminology (Dewar 2003, as cited in Rassin, 2006). Because of this, it is deemed beneficial if a family member or a nurse is present and it is helpful when written information is provided. Studies have advised that it is best not to give information about life expectancy because, as mentioned previously, it can be difficult to predict. Lying to patients would cause them to lose confidence in the caregiver but encouraging words are important (Muller, 2002, as cited in Rassin, 2006). Carter (2001) added that it is best to avoid giving blunt facts or raising hopes that are unrealistic. It takes time for the news to sink in and being present with the patient allows the patient security that helps them to express their emotions. Often they have a fear of loss of control.

What I have found to be useful information for my patients and something they have appreciated, is knowing that cancer treatments has improved drastically over the years and there are many more patients whose cancers are cured or put into permanent or temporary remission. It is important to keep things in perspective and not give false reassurance. Some patients were told that they only had a few months to live when in fact they ended up living much longer. When patients have professed their initial fears of death I have responded that "no two people are alike" because there is a broad spectrum of illness and recovery, some doing better than expected and some perhaps not. I may tell them that I hope that they do well and prove the odds wrong if they have been given a poor prognosis because it is believed that hope is important when the patient has just been told untoward news. Denial is a natural and temporary response followed by anger, fear of the unknown and anxiety, and mourning their losses. Adjustment takes time.

As nurses we need to be sensitive when asking questions and listen extremely well because good communication is imperative to reducing some of the stress the patient encounters. Taking a health history should include how the person copes with stress, and completing a thorough physical exam is part of the nursing intervention. Being able to differentiate between depression and side effects of cancer and treatment can be difficult but the possibility must not be ignored and should be taken seriously and investigated.

The patient will undergo diagnostic studies depending on the type of cancer suspected. An explanation of routine tests will serve to allay some fears that patients may have.

4.2 Making Decisions

Patients and family members are better able to make decisions when well informed. Nurses are instrumental in helping those affected by cancer understand their disease, navigate the system and guide them to supportive services to help maintain their QOL throughout the course of their illness. The field of psychosocial oncology brings into context the psychosocial, functional and spiritual aspects of the clients experience with cancer (Canadian Association of Psychosocial Oncology, 2008).

Rassin (2006) advised caregivers to accompany the patients to their appointments because the patients are often overwhelmed. Asking questions will help clarify the role of caregiver and when talking on the phone it is a good idea for caregivers to have records in front of them and to write down what is said. Rassin (2006) also stated that seeking another opinion is appropriate and the primary physician will likely support your decision to do so. Sometimes it is warranted for patients to get a second opinion, particularly if they do not feel comfortable with their oncologist as it is important for them to be able to relate to the oncologist and understand what the diagnosis entails. Some patients want to know more and some are content with being unaware of the complete picture. It is best that nurses respect the patient's choice and only provide information if it is requested.

4.3 Caregiver Needs

4.3.1 The family. With so many new cases each year, informal family caregivers may not be prepared for the role after hospitalization and will likely require education and support (Creedle et al., 2012). Their study indentified some examples of support required for caregivers such as dealing with feelings, identifying infection and helping to deal with side effects. They found that individual support reduced caregiver burden and psychological distress. A patient and family who feel a sense of support and being cared for benefit in health and illness because this is a powerful psychosocial factor.

Family members can feel helpless and need support to accept what comes and to adapt over time to new situations. Most people cannot talk openly about the illness and their feelings and initially they try to cheer up the patient too quickly to try to say the right thing. This can lead to tension and misunderstanding however anxiety may decrease if patients and families can communicate honestly with one another. Nurses can strengthen the family's connectedness and foster collaboration with the health care team.

Families undergo huge adjustments when faced with serious illness. Financial strain is perhaps the greatest stressor combined with role alterations. Spousal responsibilities are often reversed and it's a balancing act to try and maintain normalcy within the relationship. The healthy partner expresses suffering similar to the patient and his or her ability to cope and provide emotional support will either bring the couple closer together or divide them.

Adolescents may be affected because the major life cycle task of weaning children from parents is interrupted and the adult children become caregivers or join the workforce to contribute monetarily.

Families need to be supported in being flexible and adapting to the many changes that go hand in hand along the trajectory of the illness. Strengths and resources include understanding what is happening and being there by listening, and being emotionally present even if the patient turns inward to "recharge" at times. Staying physically close and accepting their feelings and letting them know they are still loved and understood is important. Allowing the ill person to maintain as much control of his or her life as possible is empowering to the patient.

4.3.2 The nurse. Encouraging the patient to ask questions and gain understanding helps them to feel less vulnerable and serves to empower them. It is important to respect that some patients may want to be an active part of the health care team whereas others may choose to be passive. Our role is to clarify their concerns and help to ensure their needs are met. Educating the patient that it is important to report symptoms creates a cohesive, collaborative relationship. Providing welcomed knowledge serves to promote patient independence, improve self esteem, and provide encouragement to continue to battle the disease.

Observing the extent to which the partner is involved may be an indicator of the amount of psychological support the ill person might receive. The involvement of the partner in treatment planning and the extent of the partners' contact when the patient is hospitalized provide data about the relationship.

The nurse can emphasize personal and supportive strengths the patient has and normalize their feelings focusing on living with the cancer and seeking more information for coping instead of focusing on death. She or he can involve social support systems when required. Above all and most importantly, she can maintain communication. In advanced stages of disease the nurse can support patients to find ways of giving meaning to their lives. Palliative patients have learned to hope for many things: acceptance of the illness, to clear up any loose ends including funeral arrangements, to visit loved ones, and finally being able to die with loved ones present.

4.3.3 Providing support. Nurses can assess the level of anxiety and plan appropriate interventions. Asking open-ended questions elicits perceptions of the illness from patients and family members. "How has your illness impacted your daily life?" "What do you think your illness does to you?" "What do you fear most about your illness?" Patients need to have their fears validated as normal and reframing of negative self-talk to see obstacles as challenges with new possibilities is something the nurse can promote. An example would include rephrasing negative thoughts of being unattractive when having a colostomy to a better way of thinking such that sexuality is more than the appearance of the patients' abdomen.

There are many techniques for reducing stress and improve coping skills such as music therapy, controlled breathing exercises, yoga, guided imagery, humour, prayer, nature walks, biofeedback, meditation including mindfulness meditation, psychotherapy, psychoeducation, hypnosis, and self-hypnosis. Support group such as “Hope and Cope” in Montreal are beneficial for reducing anxiety and improving overall outlook and there is an abundance of online support available such as the Canadian Cancer Society website (see the list in Appendix A).

Individual counselling can be arranged by referral from nursing staff members or physicians. If prescribed, pharmacologic interventions for anxiety are most often from the benzodiazepine family of medications such as lorazepam (Ativan). Assessment of patients on medication is required and keeping an eye out for depression is important. The Beck Depression Inventory, Primary Care Version is a brief one-page assessment scale used for screening to determine if further intervention is necessary. Cancer patients may experience “situational depression” which lasts a couple of weeks and is managed by an oncology nurse or health care team. By the same token, family members may need to be monitored as well for similar issues. Stenberg et al., (2012) noted that family caregivers need to be connected to internet based support and they require assistance. They state that an online support system exists to help patients and feel that a similar web-based support system would benefit caregivers in the same way, adding that caregivers would benefit from information on symptom management and professional support. I concur and am certain that a web-based video handbook would be beneficial to nurses and caregivers alike.

4.3.4 Secondary Traumatic Stress (STS). Patients, nurses and family members alike can succumb to STS. Quinal et al., (2009) compared oncology nurses with those nurses in ER and social workers to evaluate post-traumatic stress disorder (PTSD). The outcome was that ER nurses scored almost double (33%) than the other two groups. Empathy was described as a risk factor as was a previous history of personal traumatisation. They also surveyed 43 staff members in oncology that shed light on the extent of their caregiver stress. When studying the effects of cancer-care stress, the authors referred to STS, that "results from exposure to persons who have experienced trauma and from giving care to such persons" (Quinal et al., 2009). Some symptoms that have been documented were difficulty sleeping, intrusive thoughts of patients, and thinking about death. This can lead to depression and burnout. The authors concluded that it is important to build awareness so that these problems can be recognized and interventions can be provided (Quinal et al., 2009). Early intervention is a proactive approach and an assessment tool is valuable to identify caregiver needs.

4.3.5 Needs Assessment Tools. Shin et al. (2011) developed a tool for caregivers of cancer patients (CNAT–C). One of the advantages of a needs assessment over a QOL evaluation is that the caregivers can identify their own needs and the health care providers can direct them towards professional care that is required. Assessment and intervention is crucial. As noted in the study by Hodges et al. (2005), early intervention with the patient and caregiver helped to prevent the onset of psychological distress in both members. Another tool designed to effectively evaluate caregivers need for support is called the Supportive Care Needs Survey—Partners and Caregivers (SCNS-P&C). This is a multidimensional analysis that looks at the following four domains: Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs, and Information Needs (Girgis, Lambert, & Lecathelinais, 2011).

The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) developed by Siminoff et al. (2008) is an effective tool that evaluates levels and types of communication between caregivers and patients.

Chapter 5

Skills for Nurses and Caregivers

5.1 Learning to Communicate

The ability to communicate effectively is imperative because there is so much emotional strain. Unmet communication needs between caregivers and patients is a common occurrence therefore proper communication will enhance the ability to cope with the stress of cancer. The subject of cancer is so delicate one often holds back instead of speaking which can escalate tension. Above all, being a good listener, just being there in the moment, is sometimes all that is needed. If the opportunity lends itself for an open dialogue there are guidelines in place to facilitate meaningful conversation.

Family members do not usually talk to one another about the illness but if they do they may fare better in managing it. Those persons who have always had good communication skills tend to fare better but the nurse may be able to let members know that it is normal to stay quiet to protect one another. Part of nursing is to encourage family members to be open with their feelings, listen to each other's experiences and accept them, and promote empathy within the family. Honest communication helps the patient decide how to respond to the illness and manage it. In saying that, it is possible to support one another without talking about the illness. Silence, therapeutic touch, and just being there have value.

5.2 What do I Say? Who Can I Talk to?

What do I say? Shall I say "I'm sorry you have cancer. How are you managing with it?" Do I ignore it completely like the elephant in the room although we both know what is going on? Do I say, "How are you doing?" and see what happens? Do I not call at all and wait for them to call me when they are ready?

Some questions that were identified in a study on preparing a nursing program for cancer care helped the students to interact with and understand their cancer patient. They asked their patients, “What have you learned as a result of your illness? What are your greatest strengths? What is your philosophy for getting through the rough times? What do you want to accomplish most in your life now?” (Purnell et al., 2004, p. 305). Knowing how to begin is the first part of the equation.

Nurses are in a good place to facilitate conversation because they are in close proximity to the patient and family. Simply asking “Has anyone else in your family had cancer?” can begin a conversation and give the nurse insight into their perspective of the illness, myths, and understanding. This can be asked of family members as well. Families need acknowledgment that they are doing the best they can and should be provided with resources for community support and counseling in the beginning.

Before I became a nurse, my husband and I had a friend who had malignant melanoma. Knowing his prognosis was poor, we did not know what to say to him therefore we stopped calling him for a couple of months. When we finally went to visit him, we confessed that we had not called because we felt uncomfortable. He told us that many of his friends had stopped calling because they did not know what to say and he implored us to continue calling. He asked us to just call and say “Hi, how are you doing?” stating that was all he needed, and that not calling was doing him a tremendous disservice. If he didn’t feel like talking, he said he would ask us to call back, and to please make sure to do so. This was excellent advice. Just keeping in touch provides valuable support and is very meaningful to the person who is ill and may be feeling alienated at times.

5.3 Methods of Effective Communication

When interacting with the patient for the first time the nurse must make every effort to validate the patient's feelings and try not to provide premature assurance. Body language, effective eye contact, active listening and a caring touch show interest and empathy. Wittenberg-Lyles, Goldsmith, and Ferrell (2013) noted that few resources and communication programs are available to teach nurses to properly to assess and communicate effectively with patients. Their study revealed that oncology nurses felt they lacked skills to help the patient deal with the impact of cancer, family members in denial, sexual health, survivorship issues and fear of death. The authors proposed an innovative program for nurses called COMFORT which consisted of seven modules: C-communicating from a narrative approach, O-orienting to the health literacy levels and cultural diversity of patients/families, M-mindful presence, F-family caregiver communication, O-openings that allow for patient/family transition in care, R-relating and building trust, and T-team. It is a guide to communication techniques that provides very helpful suggestions and lead-in examples for caregivers (Wittenberg-Lyles et al. (2013).

Caution should be exercised because effective communication requires skill and simply repeating back the patient's statements will give them a sense that there is a lack of understanding. The key point to emphasize when communicating with cancer patients is to listen well and find out what the patient needs and wants. Some will want information about their disease and some will not. Care should be organized according to the wishes of the patient. Encouraging them to make as many decisions as they can by having as much dialogue as possible is important, because they need someone to talk to and rely on.

References

Alfes, C. M. (2011). Evaluating the use of simulation with beginning nursing students. *Journal of Nursing Education, 50,* 89-93.

Barnett, M.L. (2001), Fatigue. In S. E. Otto, (Ed.), *Oncology nursing* (4th ed, pp. 787-801). St. Louis, MO: Mosby.

Bender & Rosenzweig (2010). Cancer. In Lewis et. al., (Eds). *Medical–surgical nursing in Canada: Assessment and management of clinical problems,* (2nd Canadian ed, pp. 322-361). Oshawa, ON: Mosby.

Canadian Cancer Society, (n.d.). Retrieved from http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=qc

Carroll-Johnson, R. M. (2010). Congratulations and welcome to the world of oncology nursing. *Oncology Nursing Forum, 37,* 379.

Carter, P. (2001). A not-so-silent cry for help. *Journal of Holistic Nursing, 19,* 271-284.

Charalambous, A., & Kaite, C. (2013). Undergraduate nursing students caring for cancer patients: Hermeneutic phenomenological insights of their experiences. *BMC Health Services Research, 13*(1), 1-13.

Childress, S., & Gorder, D. (2012). Oncolgy nurse internships: A foundation and future for onccology nursing practice? *Oncology Nursing Forum, 39,* 341-344.

Cipolletta, S., Shams, M., Tonello, F., & Pruneddu, A. (2013). Caregivers of patients with cancer: Anxiety, depression and distribution of dependency. *Psycho-Oncology, 22*(1), 133.

Clinical Communication Collabortative (2013). Retrieved from http://www.clinicalcc.com/comfort-nurse/

Copp, G., Caldwell, K., & Atwal, A. (2007). Preparation for cancer care: Perceptions of newly qualified health care professionals. *European Journal of Oncology Nursing, 11,* 159-167.

Creedle, C., Leak, A., Deal, A., Walton, A. M., Talbert, G., Riff, B., & Hornback, A. (2012). The impact of education on caregiver burden on two inpatient oncology units. *Journal of Cancer Education, 27,* 250-256.

French-Rosas, L. (2001). Improving the recognition and treatment of cancer-related posttraumatic stress disorder. *Journal of Psychiatric Practice, 17,* 270-276.

Gaugler, J., Linder, J. F., Given, C., Kataria, R., Tucker, G., & Regine, W. F. (2009). Family cancer caregiving and negative outcomes: The direct and meditational effects of psychosocial resources. *Journal of Family Nursing, 15,* 417-444.

Geffen, J. R. (2010). Integrative oncology for the whole person: A multidimensional approach to cancer care. *Integrative Cancer Therapies, 9,* 105-121.

Gilbert, E., Ussher, J. M., & Perz, J. (2010). Renegotiating sexuality and intimacy in the context of cancer: the experiences of carers. *Archives of Sexual Behavior, 39,* 998-1009.

Girgis, A., Lambert, S., & Lecathelinais, C. (2011). The supportive care needs survey for partners and caregivers of cancer survivors: Development and psychometric evaluation. *Psycho-Oncology, 20,* 387.

Hermann, C. P., Conner, A. L., & Mundt, M. H. (2008). Enhancing cancer nursing education through school of nursing partnerships: the cancer nursing faculty fellows program. *Journal of Nursing Education, 47,* 275-278.

Hickey, K., *Cancer Care Preparedness Survey Questionnaire,* http://www.surveymonkey.com/s/ (March, 2013).

Hodges, L., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science and Medicine, 60*(1), 1-12.

Kav, S., Citak, E. A., Akman, A., & Erdemir, F. (2013). Nursing students' perceptions towards cancer and caring for cancer patients in Turkey. *Nurse Education in Practice, 13*(1), 4-10.

Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69,* 283.

Lewis, F. M. (2006). The effects of cancer survivorship on families and caregivers. *American Journal of Nursing, 106,* 20-25.

Mayo Clinic School of Health Sciences. www.mayo.edu/mayo-school-of-health-sciences-documents/pharm-ppp-hematology-oncology.pdf). Retreived March, 2013.

McLennan, S., (2013). Oncology nurses' narratives about ethical dilemmas and prognosis-related communication in advanced cancer patients. *Cancer Nursing, 36,* 114-121.

McMillan L., & Shannon, D. (2011). Program evaluation of nursing school instruction in measuring students' perceived competence to empathically communicate with patients. *Nursing Education Perspectives, 32,* 150-154.

Murray S., Kendall, M., Boyd, K., Grant, L., Highet, G., & Sheikh, A. (2010). Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews. *British Medical Journal, 34,* 1410.

National Cancer Institute (2007). http://www.cancer.gov/cancertopics/pdq/supportivecare/communication/patient

Northfield, S., & Nebauer, M. (2010). The caregiving journey for family members of relatives with cancer. *Clinical Journal of Oncolgy Nursing, 14,* 567-577.

Osse, B. H., Myrra, J. F., Schade, E., & Richard, P. T. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing, 29,* 378-378.

Papadopoulos, A., Vrettos, I., Kamposioras, K., Anagnostopoulos, F., Giannopoulos, G., & Pectasides, D. (2011). Impact of cancer patients' disease awareness on their family members' health-related quality of life: A cross-sectional survey. *Psycho-Oncology, 20,* 294.

Purnell, M. J., Walsh, S. M., & Milone, M. A. (2004). Oncology nursing education: Teaching strategies that work. *Nursing Education Perspectives, 25,* 304-308.

Quinal, L., Harford, S., & Rutledge, D. N. (2009). Secondary traumatic stress in oncology staff. *Cancer Nursing, 32,* E1-7.

Rassin, M., Levy, O., Schwartz, T., & Silner, D. (2006). Caregivers' role in breaking bad news: Patients, doctors, and nurses' points of view. *Cancer Nursing, 29,* 302.

Shin, D., Park, J-H., Shim, E-J., Choi, J-Y., Kim, S. G. & Park, E-C (2011). The development of a comprehensive needs assessment tool for cancer-caregivers in patient-caregiver dyads. *Psycho-Oncology, 20,* 1342.

Siminoff, L. A., Zyzanski, S. J., Rose, J. H., & Zhang, A. Y. (2008). The cancer communication assessment tool for patients and families (CCAT-PF): A new measure. *Psycho-Oncology, 17,* 1216.

Stenberg, U., Ruland, C. M., Olsson, M., & Ekstedt, M. (2012). To live close to a person with cancer-experiences of family caregivers. *Social Work in Health Care, 51,* 909.

Swanberg J. (2006). Making it work: Informal caregiving, cancer, and employment. *Journal of Psychosocial Oncology, 24,* 1-18.

Swensen, C. J. (2001). Pain Management. In S. E. Otto, (Ed.), *Oncology Nursing* (4th ed: pp. 865-916). St. Louis, MO: Mosby.

Tishleman, C., Bergenmar, M., Bernhardson, B.-M., Blomberg, K., Börjeson, S., Foderus, H., & Ternestedt, B.-M. (2008). Using undergraduate nursing students as mediators in a knowledge transfer programme for care for patients with advanced cancer. *European Journal of Cancer Care, 17,* 253-260.

Vanderwerker , L.C., Laff, R., Kadan-Lottick, N. S., McColl, S., Prigerson, H. (2005). Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. *American Society of Clinical Oncology 23, 6899-6907.* doi:10.1200/JCO.2005.01.370JCO

WHO (2013). Cancer prevention. http://www.who.int/cancer/prevention/en/

Wittenberg-Lyles, E., Goldsmith, & J., Ferrell, B. (2013). Oncology nurse communication barriers to patient-centered care. *Clinical Journal of Oncology Nursing*, *17,* 152-8.

Table 1

Employment Status

Which of the following categories best describes your current employment status?

Employment Status	Frequency
Working as a CPN (part-time occasional)	3 (21%)
Working as a CPN (full-time)	1 (7%)
Working as a Nurse (part-time occasional)	3 (21%)
Working as a Nurse (full-time)	6 (43%)
I am on maternity leave	1 (7%)
I am on sick leave	0
Other	0

Table 2

Areas of Practice

Select from the list below the areas in which you have worked as a CPN or as a nurse since you graduated from your Nursing program. You may select more than one.

Area	Frequency
Geriatrics	1 (7%)
Oncology	8 (57%)
Medicine	3 (21%)
ICU	0
Surgery	0
Psychiatry	0
Emergency department	0
Paediatrics	0
Long term care	0
Other please specify	2 (14%)

Table 3

Education and Age Bracket

Which of the following describes your nursing education and your age bracket?

Education	Frequency
CEGEP or college	8 (57%)
University	6 (43%)
Post Graduate studies	0

Age	Frequency
19 -20	1 (7%)
21-25	3 (21%)
26-30	8 (57%)
31-40	2 (14%)
41-50	0
51-60	0

Table 4

Preparedness for Cancer Care

In terms of working with cancer patients, the education I received in my Nursing program resulted in my being:

Likert Scale Measurement	Frequency
Very well prepared	0
Very prepared	1 (7%)
Prepared	5 (35%)
Somewhat prepared	8 (57%)
Not prepared at all	0
Don’t know	0

Table 5

Areas Requiring Additional Information

I would like to have had more information in my Nursing program in the following areas: Check any/all that apply.

Area	**Frequency**
Disease process	8 (57%)
Causes of cancer	5 (36%)
Chemotherapy	7 (50%)
Radiation Therapy	7 (50%)
Biological therapy	3 (21%)
Bone marrow and Stem Cell Transplant	6 (43%)
Alternative therapies	4 (29%)
Side effects/management of treatment	8 (57%)
Communication with cancer patients (survivors/remission)	9 (64%)
Communication with cancer patients (palliative)	9 (64%)
Communication with family members/caregivers	9 (64%)
Recognizing patient needs (stress related)	9 (64%)
Recognizing caregiver needs (stress related)	9 (64%)
Recognizing nursing needs (stress related)	6 (43%)
Learning to reduce stress in self and/or in others	8 (57%)
Assisting the caregiver (family /friend)	5 (36%)
Coping with loss/death	9 (64%)

Table 6

Workplace Support

I felt supported in my current workplace (Oncology) when I first started.

Likert Scale Measurement	Frequency
Strongly agree	4 (26%)
Agree	9 (64%)
Disagree	1 (7%)
Strongly agree	0
Don’t know	0

Table 7

Methods of Workplace Support

How are nurses supported in your workplace? Check all that apply.

Methods of support	Frequency
Structured orientation program	10 (71%)
Structured mentorship program	7 (50%)
Periodic meetings to support new nurses	7 (50%)
Periodic meetings to support experienced nurses	5 (36%)
Periodic in-services to educate nurses	10 (71%)
Accessible assistance from resource nurse or nurse manager	11 (79%)

Table 8

Months/years worked in Oncology

Indicate in the boxes provided how many months or years you have been working as a Nurse since you graduated from your Nursing program and the length of time in Oncology.

Months/Years as Nurse	Months/Years in Oncology	Age	Preparedness
4 years	2 years	26	SW
4 months	4 months	19	P
1 year	1 year	26 U	SW
8 months	8 months	26	SW
4 months	4 months	26	SW
6 years	6 years	26	P
5 years	5 years	21	SW
7 years	5 years	26	P
3 months	3 months	31	SW
6 years	4 years	26 U	P
4 years	3 years	21 U	P
14 months	14 months	21 U	SW
8 years	1 year	31 U	SW

Note. U: University-educated.

Likert scale VP: Very Prepared, P: Prepared, SW: Somewhat Prepared

Table 9

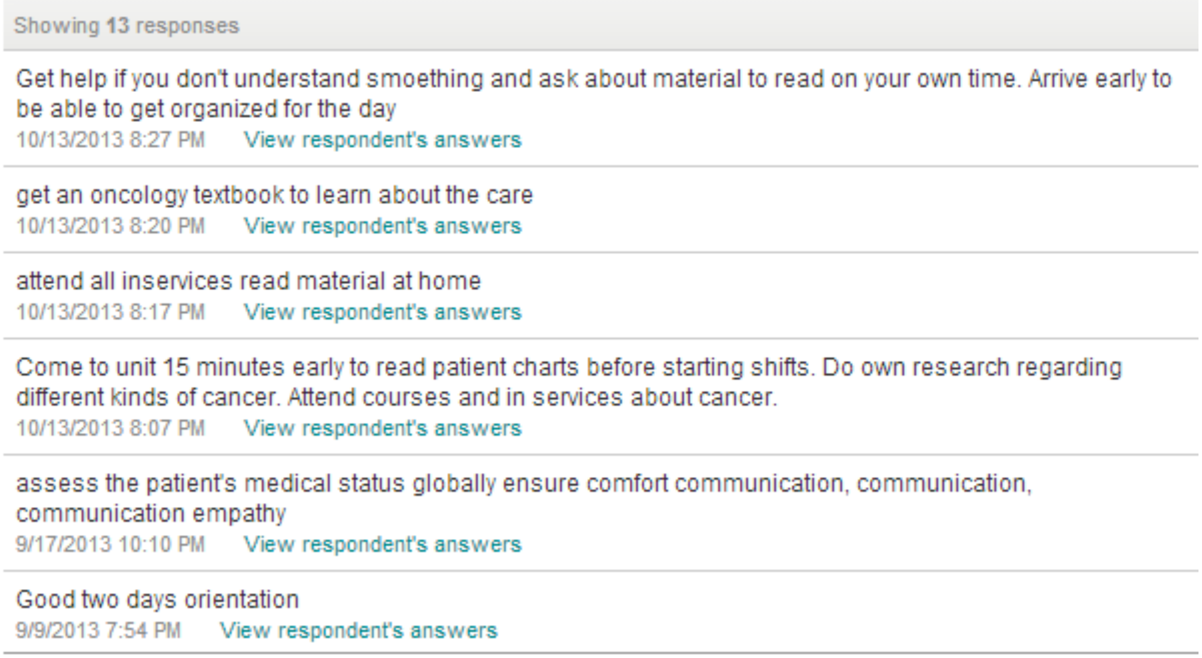
Comparison of CEGEP and University Preparedness

Rating	University	College
Very prepared	1 (17%)	0
Prepared	2 (33%)	3 (37%)
Somewhat prepared	3 (50%)	5 (63%)

Table 10

Suggested Strategies for New Nurses

What strategies would you suggest to new Nursing graduates so they can successfully transition to working with cancer patients when they first start as a CPN or a Nurse?



Showing **13** responses

Get help if you don't understand smoething and ask about material to read on your own time. Arrive early to be able to get organized for the day
10/13/2013 8:27 PM View respondent's answers

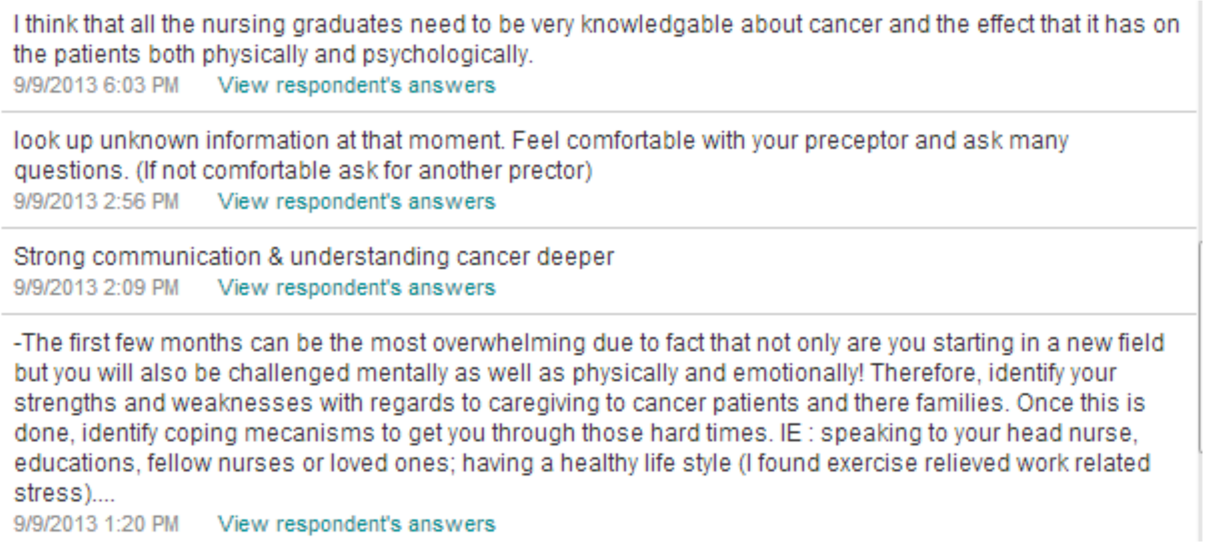
get an oncology textbook to learn about the care
10/13/2013 8:20 PM View respondent's answers

attend all inservices read material at home
10/13/2013 8:17 PM View respondent's answers

Come to unit 15 minutes early to read patient charts before starting shifts. Do own research regarding different kinds of cancer. Attend courses and in services about cancer.
10/13/2013 8:07 PM View respondent's answers

assess the patient's medical status globally ensure comfort communication, communication, communication empathy
9/17/2013 10:10 PM View respondent's answers

Good two days orientation
9/9/2013 7:54 PM View respondent's answers

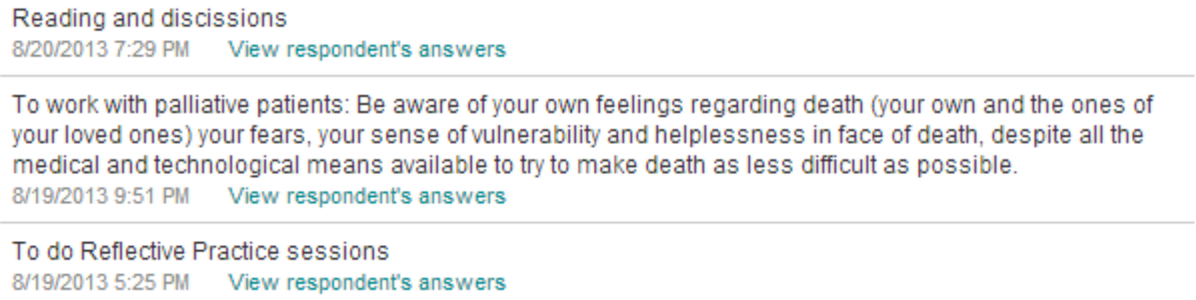


I think that all the nursing graduates need to be very knowledgable about cancer and the effect that it has on the patients both physically and psychologically.
9/9/2013 6:03 PM View respondent's answers

look up unknown information at that moment. Feel comfortable with your preceptor and ask many questions. (If not comfortable ask for another prector)
9/9/2013 2:56 PM View respondent's answers

Strong communication & understanding cancer deeper
9/9/2013 2:09 PM View respondent's answers

-The first few months can be the most overwhelming due to fact that not only are you starting in a new field but you will also be challenged mentally as well as physically and emotionally! Therefore, identify your strengths and weaknesses with regards to caregiving to cancer patients and there families. Once this is done, identify coping mecanisms to get you through those hard times. IE : speaking to your head nurse, educations, fellow nurses or loved ones; having a healthy life style (I found exercise relieved work related stress)....
9/9/2013 1:20 PM View respondent's answers



Reading and discissions

8/20/2013 7:29 PM View respondent's answers

To work with palliative patients: Be aware of your own feelings regarding death (your own and the ones of your loved ones) your fears, your sense of vulnerability and helplessness in face of death, despite all the medical and technological means available to try to make death as less difficult as possible.

8/19/2013 9:51 PM View respondent's answers

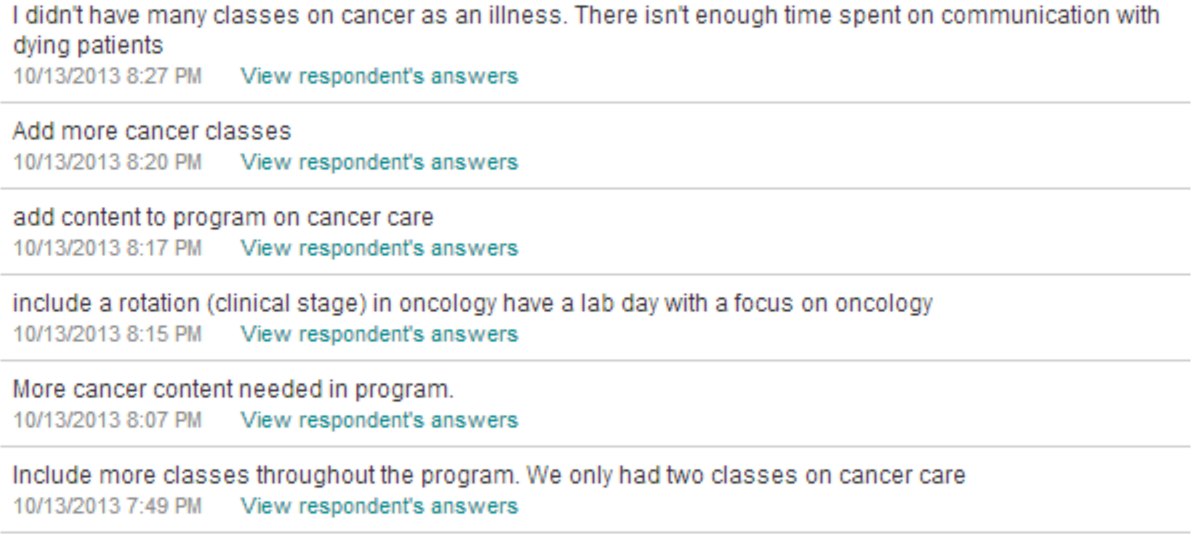
To do Reflective Practice sessions

8/19/2013 5:25 PM View respondent's answers

Table 11

Suggestions to Improve the Nursing Program

Are there any suggestions you would like to make on how to improve the Nursing Program at the institution you graduated from?



I didn't have many classes on cancer as an illness. There isn't enough time spent on communication with dying patients
10/13/2013 8:27 PM View respondent's answers

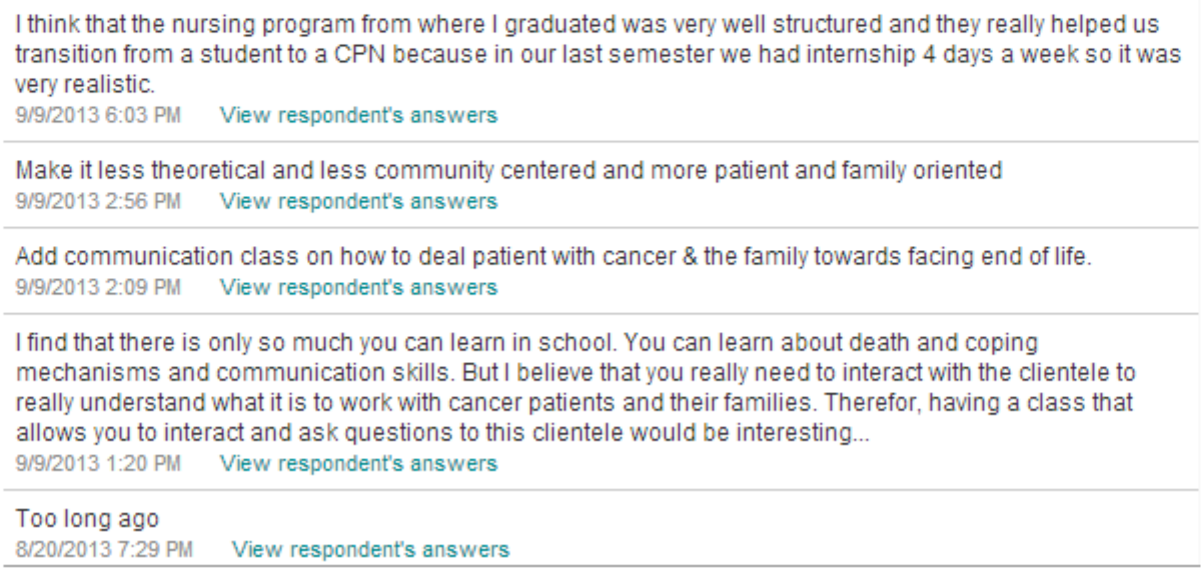
Add more cancer classes
10/13/2013 8:20 PM View respondent's answers

add content to program on cancer care
10/13/2013 8:17 PM View respondent's answers

include a rotation (clinical stage) in oncology have a lab day with a focus on oncology
10/13/2013 8:15 PM View respondent's answers

More cancer content needed in program.
10/13/2013 8:07 PM View respondent's answers

Include more classes throughout the program. We only had two classes on cancer care
10/13/2013 7:49 PM View respondent's answers



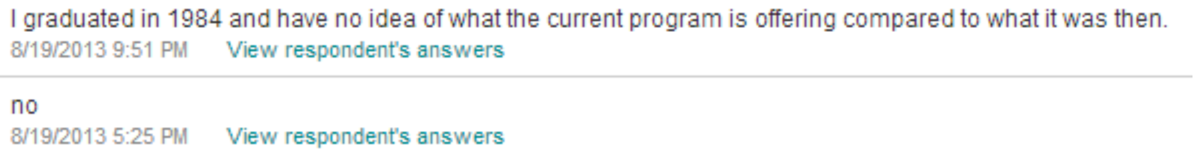
I think that the nursing program from where I graduated was very well structured and they really helped us transition from a student to a CPN because in our last semester we had internship 4 days a week so it was very realistic.
9/9/2013 6:03 PM View respondent's answers

Make it less theoretical and less community centered and more patient and family oriented
9/9/2013 2:56 PM View respondent's answers

Add communication class on how to deal patient with cancer & the family towards facing end of life.
9/9/2013 2:09 PM View respondent's answers

I find that there is only so much you can learn in school. You can learn about death and coping mechanisms and communication skills. But I believe that you really need to interact with the clientele to really understand what it is to work with cancer patients and their families. Therefor, having a class that allows you to interact and ask questions to this clientele would be interesting...
9/9/2013 1:20 PM View respondent's answers

Too long ago
8/20/2013 7:29 PM View respondent's answers



I graduated in 1984 and have no idea of what the current program is offering compared to what it was then.
8/19/2013 9:51 PM View respondent's answers

no
8/19/2013 5:25 PM View respondent's answers

Appendix A

Support Groups and Resources

Bauer-Wu, Susan; Mindfulness Meditation: Oncology Journal found on http://www.cancernetwork.com. (Oncology Nurse Edition, Vol. 24, No. 10, October 19, 2010).

Canadian Cancer Association: http://www.cancer.ca/en/cancer-information/cancer-101/

Canadian Virtual Hospice: Mindfulness and Reflective Practice: Enriching personal and professional growth. http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Cancer Care Ontario: https://www.cancercare.on.ca/toolbox/pfac/

Hope and Cope, Jewish General Hospital Montreal: http://www.jgh.ca/en/HopeCope

Mayo Clinic: http://www.mayoclinic.com/health/cancer/DS01076

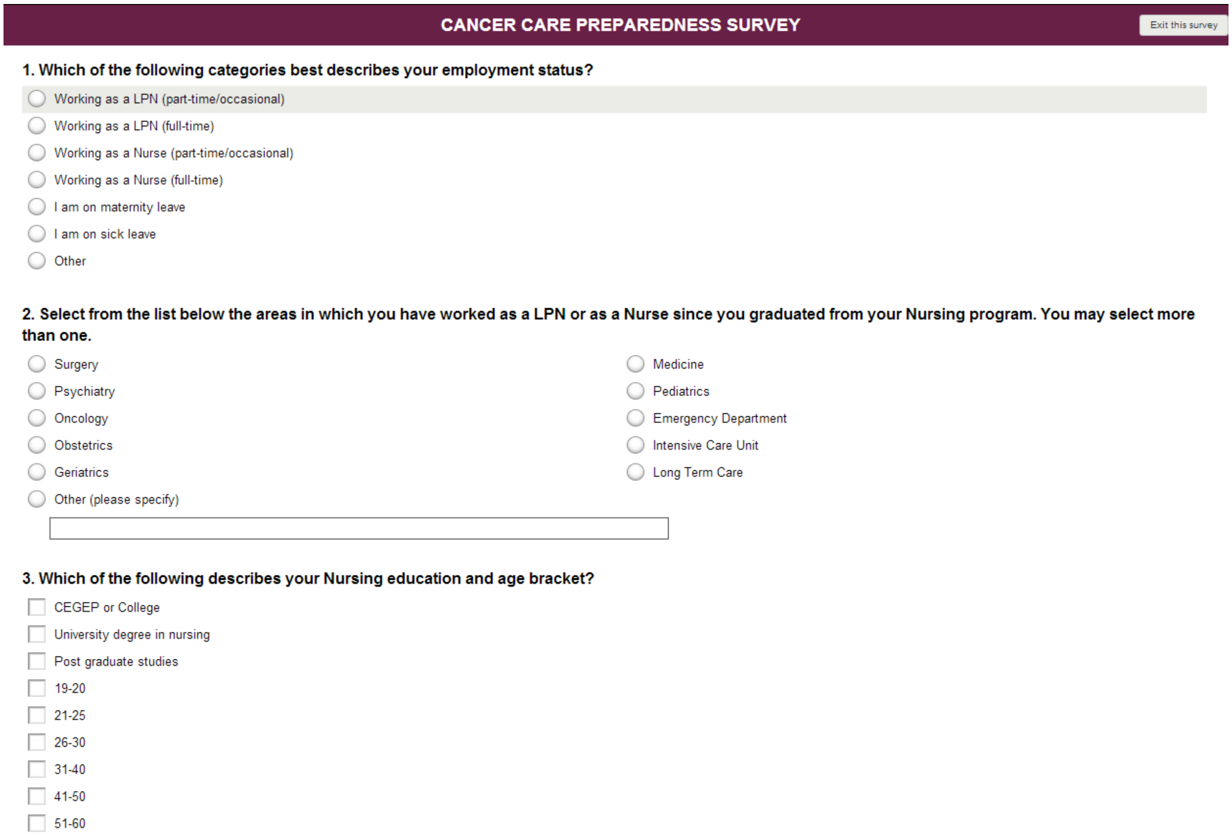
National Cancer Institute: http://www.cancer.gov

OncoLink Cancer Resources for Patients and Health Care Professionals: http://www.oncolink.org

Webmd Cancer Center: http://www.webmd.com/cancer/

Appendix B

Cancer Care Preparedness Survey: Questionnaire



CANCER CARE PREPAREDNESS SURVEY

1. Which of the following categories best describes your employment status?

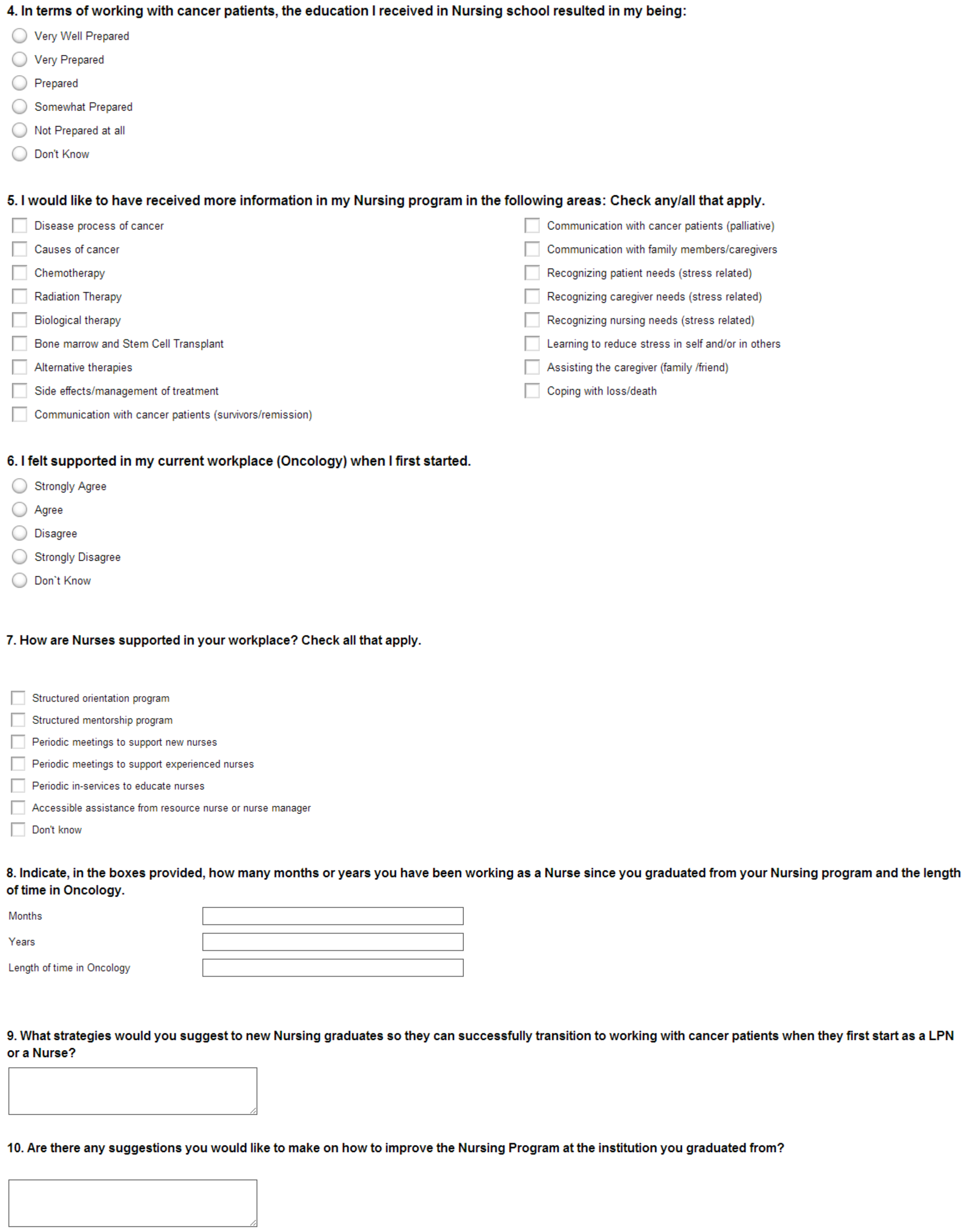
○ Working as a LPN (part-time/occasional)
○ Working as a LPN (full-time)
○ Working as a Nurse (part-time/occasional)
○ Working as a Nurse (full-time)
○ I am on maternity leave
○ I am on sick leave
○ Other

2. Select from the list below the areas in which you have worked as a LPN or as a Nurse since you graduated from your Nursing program. You may select more than one.

○ Surgery
○ Psychiatry
○ Oncology
○ Obstetrics
○ Geriatrics
○ Other (please specify)
○ Medicine
○ Pediatrics
○ Emergency Department
○ Intensive Care Unit
○ Long Term Care

3. Which of the following describes your Nursing education and age bracket?

☐ CEGEP or College
☐ University degree in nursing
☐ Post graduate studies
☐ 19-20
☐ 21-25
☐ 26-30
☐ 31-40
☐ 41-50
☐ 51-60



4. In terms of working with cancer patients, the education I received in Nursing school resulted in my being:

○ Very Well Prepared
○ Very Prepared
○ Prepared
○ Somewhat Prepared
○ Not Prepared at all
○ Don't Know

5. I would like to have received more information in my Nursing program in the following areas: Check any/all that apply.

☐ Disease process of cancer
☐ Causes of cancer
☐ Chemotherapy
☐ Radiation Therapy
☐ Biological therapy
☐ Bone marrow and Stem Cell Transplant
☐ Alternative therapies
☐ Side effects/management of treatment
☐ Communication with cancer patients (survivors/remission)
☐ Communication with cancer patients (palliative)
☐ Communication with family members/caregivers
☐ Recognizing patient needs (stress related)
☐ Recognizing caregiver needs (stress related)
☐ Recognizing nursing needs (stress related)
☐ Learning to reduce stress in self and/or in others
☐ Assisting the caregiver (family /friend)
☐ Coping with loss/death

6. I felt supported in my current workplace (Oncology) when I first started.

○ Strongly Agree
○ Agree
○ Disagree
○ Strongly Disagree
○ Don`t Know

7. How are Nurses supported in your workplace? Check all that apply.

☐ Structured orientation program
☐ Structured mentorship program
☐ Periodic meetings to support new nurses
☐ Periodic meetings to support experienced nurses
☐ Periodic in-services to educate nurses
☐ Accessible assistance from resource nurse or nurse manager
☐ Don't know

8. Indicate, in the boxes provided, how many months or years you have been working as a Nurse since you graduated from your Nursing program and the length of time in Oncology.

Months ☐
Years ☐
Length of time in Oncology ☐

9. What strategies would you suggest to new Nursing graduates so they can successfully transition to working with cancer patients when they first start as a LPN or a Nurse?

10. Are there any suggestions you would like to make on how to improve the Nursing Program at the institution you graduated from?